NHS HWE ICB Primary Care Board Meeting

[Public Session]

Thursday 28 September 2023

Conference Room 2, The Forum, Hemel Hempstead

HP1 1DN

09:30 -12:00

Hertfordshire and West Essex Integrated Care Board

Meeting Book - ICB Primary Care Board Meeting [Public Session] Thursday 28 September 2023

NHS HWE ICB Primary Care Board meeting held in Public

09:30	1. Welcome, apologies and housekeeping		Chair
09:30	2. Declarations of interest		Chair
09:35	3. Minutes from the last meeting - Thursday 27 July 2023	Approval	Chair
	4. Action Tracker		Chair
9:40	5. Questions from public		Chair
09:45	6. Directorate Highlight Report	Discussion/Information	Avni Shah
10:00	7. Risk Register	Discussion/Information	Andrew Tarry
10:10	8. Primary Care Transformation Reports	Discussion/Information	Place Leads
	Primary Care Transformation Report - East & North Herts		Cathy Galione
	Primary Care Transformation Report - West Essex		Philip Sweeny
	Primary Care Transformation Report - South West Herts		Roshina Khan
	11:00 - 11:15 Comfort Break		
11:15	9. Enhanced Commissioning Framework 2022/23	Discussion	Sam Williamson
11:30	10. Primary Care Contracts update: Dental plan	Discussion	Michelle Campbell
11:45	11. HealthWatch Hertfordshire / West Essex	Discussion/Information	Chloe/ Sam
	12. Minutes from Subgroups	Information	Chair
	Primary Care Digital		
	Primary Care Workforce		
11:55	13. Reflections and feedback from the meeting		Chair
12:00	Close of meeting		Chair

Herts & West Essex Strategic Framework- 2022-2027

Our mission

Better, healthier and longer lives for all

We will achieve this by

- **Improving physical and mental health across our population**
- **Tackling unequal access, experience and outcomes**
- **Enhancing productivity and value for money**
- **Ensuring the NHS supports broader social and economic development.**

In the first 3-5 years we will

- Increase healthy life expectancy, and reduce inequality
- Give every child the best start in life
- Improve access to health and care services
- Increase the numbers of citizens taking steps to improve their wellbeing
- Achieve a balanced financial position annually

The ICB will deliver this by:

- Setting direction for the NHS in Hertfordshire and West Essex
- Allocating NHS resources fairly and effectively
- Supporting, equipping, and empowering our people
- Working with and pooling resources with our partners
- Enabling improvement and driving change, with a focus on quality
- Using data and evidence to generate insight and assess impact

Hertfordshire and West Essex Integrated Care System

Hertfordshire and West Essex Integrated Care System

NHS Hertfordshire and West Essex Integrated Care Board

DRAFT MINUTES

Meeting:	**HWE ICB Primary Care Board meeting held in Public**			
	Meeting in public	☒	*Meeting in private (confidential)*	☐
Date:	**Thursday 27 July 2023**			
Time:	**09:30 – 12:30**			
Venue:	**The Forum, Hemel Hempstead and Via MS Teams**			

MINUTES

Name	Title	Organisation
Members present:		
Nicolas Small (NS) **(Meeting Chair)**	Partner Member (Primary Medical Services)	Herts and West Essex ICB
Elliot Howard Jones (EHJ)	Partner member (NHS Community Trust)	Herts and West Essex ICB
Rob Mayson (RM)	Primary Care Locality Lead – ENH	Herts and West Essex ICB
Gurch Randhawa (GR)	Non-Executive Member	Herts and West Essex ICB
Avni Shah (AS)	Director of Primary Care Transformation	Herts and West Essex ICB
Via Ms Teams:		
Prag Moodley (PM)	Partner Member (Primary Medical Services)	Herts and West Essex ICB
Rachel Joyce (RJ)	Medical Director	Herts and West Essex ICB
Elizabeth Disney (ED)	Director of Operations	Herts and West Essex ICB
In attendance:		
Leighton Colegrave (LC)	Citizen Representative, East North Herts	Herts and West Essex ICB
Marianne Hilley (MH)	Citizen Representative, South West Herts	Herts and West Essex ICB
Iram Khan (IK)	Corporate Governance Manager	Herts and West Essex ICB
Trudi Mount (TM)	Programme Director – Data and Digital	Herts and West Essex ICB
Helen Musson (HM)	Chief Officer	Hertfordshire Local Pharmaceutical Committee
Tracey Norris (TN) (minute taker)	Clerk	HFL Education

Emily Perry (EP)	Primary Care Manager – strategy and transformation	Herts and West Essex ICB
Annette Pullen (AP)	EA to Avni Shah	Herts and West Essex ICB
Andrew Tarry (AT)	Head of Primary Care Contracts	Herts and West Essex ICB
Neil Tester (NT)	Vice Chair	Healthwatch Hertfordshire
Meghan Spencer (MG)	Primary Care Co-Ordinator – Strategy & Transformation	Herts and West Essex ICB
Via MS Teams:		
Charlotte Blizzard (CB)	VCSFE Representative	Citizens Advice, Stevenage
Gopesh Farmah (GF)	Digital Clinical Lead	Herts and West Essex ICB
Cath Fenton (CF)	Consultant in Public Health	Herts County Council
James Gleed (JD)	Associate Director Commissioning Primary Care	Herts and West Essex ICB
Rachel Halksworth (RH)	Assistant Director for Primary Care Contracting	Herts and West Essex ICB
Anurita Rohilla (AR)	Chief Pharmacist	Herts and West Essex ICB
Sam Glover (SG)	Chief Executive	HealthWatch Essex
Philip Sweeny (PS)	Head of Primary Care Transformation and Integration - West Essex	Herts and West Essex ICB
Nicky Williams (NW)	Co-Chief Executive	Bedfordshire & Hertfordshire Local Medical Committee Ltd

PCB/46/23	Welcome, apologies and housekeeping
46.1	The Chair welcomed all to the meeting. He confirmed that this was not a public meeting but a meeting being held in public (members of the public were welcome to attend but were not permitted to participate). Questions from the public were welcomed in advance and there were instructions on the website explaining how to submit these.
46.2	Apologies for absence had been received from: • Joanna Marovitch, VCSFE representative – deputy Charlotte Blizzard-Welch in attendance. • Dr Ian Perry, Partner member • Dr V Raja. The meeting was declared quorate.
PCB/47/23	**Declarations of interest**
47.1	The Chair invited members to declare any declarations relating to matters on the agenda: • None declared. All members declarations are accurate and up to date with the register available on the website: Declaration of interests – Hertfordshire and West Essex NHS ICB
PCB/48/23	**Minutes from the previous meeting**
48.1	**The minutes of the last meeting held on 25 May 2023 were agreed as an accurate record.**
PCB/49/23	**Action tracker**
49.1	There were no open actions.
PCB/50/22	**Questions from the public**
50.1	A question had been received from John Wrigley about primary care workforce: 1. How many people of working age in the ICB area are qualified as GPs? 2. How many of them are working as GPs? 3. Of that number, how many are working in NHS GP surgeries? 4. Of the number working in NHS GP surgeries, how many are part-time? 5. How many vacancies for GPs are there in NHS GP surgeries?
50.2	HWE Response: Please note that the ICB only has access to the general practice workforce data via the "National Workforce Reporting Service" (NWRS). This is a system managed by NHS England whereby individual GP practices submit their workforce data on a monthly basis. This information will only be on the clinical and non-clinical staff working in respective ICB footprint. Hence, we are unable to report on total number of GPs who may be living across HWE but may not be working specifically in primary care. Based on the information from NWRS for May 2023 (the latest available), the table below provides the information of full-time equivalent GPs (including training grades/salaried/partners and at that point in time locums). Please note this is the figure for May 2023 only and will fluctuate with demands in general practice including sickness/vacancy/maternity cover where practices staffing will be adjusted to meet the demands. As per Q1, the total number of all GPs including training, partners, salaried and some locums is 1213 headcount. We are unable to report on the number of GPs that are part time. We can advise that of the headcount of 1213, the "Full Time Equivalent" is 925. This means when the hours of all full time and part time GPs is combined, there is an equivalent of 925 full time GPs. As the specific hours of a part time GP can greatly vary, we cannot use this figure to determine the precise amount of part time GPs.

	The national database does not provide us the with the number of GP vacancies per practice. However, we do know that since April 2023 191 adverts across 62 Practices and 2 PCNs was put out via primary care careers a supportive job advertising platform for practices across HWE to use to advertise for jobs in general practices. This platform is to support recruitment to all clinical and non-clinical positions. However, this is only an estimate as not all practices use Primary care Careers to advertise. Secondly as we know the, the model of general practices has changed over the last 2-3 years with the introduction of Additional Roles Reimbursement Scheme (ARRS) which include over 20 different roles to be recruited across a primary care network to provide additional capacity in general practice through a network. In addition, a number of practices have directly employed a range of clinicians such as clinical pharmacists, physiotherapists above the ARRS roles to support the delivery of health outcomes In general practice and meet the needs of the population. Since January 2023, HWE Primary care teams are working with each PCN through a commissioned PCN education team which have the responsibility to oversee the training/education of the whole workforce in general practice at a network level with a view to support recruit/retention, career development and maintain a good resilient and happy workforce. This is to support all clinical and non-clinical workforce across the PCNs. Early findings of this initiative have been positive to support the workforce in primary care with the wraparound of protected time to learn, having access to national resources for education and training through the local Primary Care workforce training hub working closely to the ICS People Board objectives.
PCB/51/23	**Directorate Highlight Report & Risk Register**
51.1	Avni Shah (AS) introduced these items (see pages 21-36 of the document pack) and highlighted the following: • The PC team were now preparing for the autumn vaccination programme (Covid boosters and Flu) and winter planning in primary care to support pressures in primary care and how this supports same day access. • There was variation in uptake across the UK for COVID vaccination particularly in the immunocompromised patients; a research project is underway to understand the barriers and identify solutions to increase take-up (this is being led by HCC Public Health Leads ob behalf of the East of England). Early findings from this project would be available by the end of August. Work continued with the lead provider (HCT) to address inequalities. • MMR vaccinations: There is a current rise in MMR infections in children. In light of this there is collaboration between the NHSE Public health team and HWE Community Childrens Services provider HCT to look at targeted approach in certain localities across Hertfordshire. Learnings from this would be shared with Essex. Further update on this at future September meeting. • Sarah Dixon and AS had led a deep dive into primary care workforce at the People Board in July. This governed general practice, community pharmacy, dentistry and optometry (see slide on page 26). Workforce plans were aligned to the People Strategy for HWE. • Our HWE PCN Education team initiative had been shortlisted for a Health Service Journal award. • Good progress was being made on recruitment and staff wellbeing across a number of PCNs. HWE were on track to have the highest number of nursing associates in the East of England. In addition: ○ The number of training practices had increased by 20%. There were now seven PCN learning organisations (up from two).

	• 34 community pharmacy leaders had been recruited. – the focus of these roles is to enhance the integration of community pharmacy with primary care. We will explore as to how to apply this to dental and optometry moving forward.AS updated the highlight on development of integration neighbourhood teams. • A successful comms and engagement event was held with over 100 citizens/patients attending to discuss the direction of travel of primary care delivery plan • Development of Patient Participation Groups (PPG) were gaining traction at both practice and PCN level. • The Risk Register had been reviewed in the light of ICB discussions on the appropriate approach to risk. Risks would be measured from a programme perspective and an updated risk register would be shared at the end of August.
51.2	Questions and comments were invited: • Vaccinations: It would be helpful to see a visual graphic of the take-up of vaccinations vs allocation of capacity and population need. This would highlight areas of inequalities. • Efficiencies could be achieved if practices and community pharmacies were able to deliver vaccinations on a patient-by-patient basis – ie combining programmes. • Recruitment: Was the team tracking the disparity between different places vis recruitment. Was it possible that inequalities were widening as some areas struggled to attract any applications? • AS agreed that this would be a useful exercise to undertake and should also consider the level of service provision as well as workforce. • Care was needed to ensure genuinely new roles were reported separately to roles which saw staff move between services within primary care. • There were district variations in different areas of provision within primary care. The PC Strategic Delivery Plan team had begun by looking at public health, and all this data (including outreach work) would be captured and linked back to inequalities. • New projects and pilots should be considered from an inequalities lens and care should be taken that new initiatives were not always in the least deprived areas. Access data should be used to identify areas where practices were struggling with recruitment. • Communications lessons could be learned from the covid spring booster campaign; community pharmacy reported too many people had been attending for their injection who were not eligible. • Q What was the timeline for delivery of the GP access comms engagement plan? Ans: The detail of the plan included the sharing of best practice as well as top-down urgent comms improvements. Health Watch and patient representatives could champion this. PPG were now in place at a practice and network level.
51.3	**The Primary Care Board noted the Directorate Highlight Report and action for AS to consider how data can be presented to show impact.**
PCB/52/23	**Primary Care Transformation**

52.1	**Primary Care Digital Priorities**
	Trudi Mount and Dr Gopesh Farmah presented the primary care digitation priorities report (see pages 37-59 of the document pack) and highlighted the following:
	• Key themes:
	  ○ Empower patients
	  ○ Implement the modern general practice model
	  ○ Reduce bureaucracy
	  ○ Building capacity
	• Challenges: funding

	• Following extensive consultation, the following seven priorities had been established:
	  ○ Digital inclusion
	  ○ Advanced telephony
	  ○ NHS App
	  ○ Automation
	  ○ Digital workforce
	  ○ Community pharmacy integration
	  ○ Infrastructure

52.2	Questions and comments were invited:
	• The Chair invited board members to consider whether the digital priorities would deliver the needed transformation in Primary Care, support the Primary Care Access Recovery Plan and whether the plans were realistic?
	• The board agreed that the digital priorities would support transformation and recovery and were realistic subject to the following caveats/potential barriers and opportunities:
	  ○ Digital improvement would depend on individual GP appetite and digital competency; this would vary from practice to practice.
	  ○ Training for all software programmes could be improved and training to be made available regularly with the staff churn.
	  ○ The lead GP in a practice was often also responsible for IT, regardless of interest or capacity. The workforce needed to have capacity and capability to ensure success.
	  ○ The creation of a digital software training team should be considered.
	  ○ Digital access was the right solution for some patients, but for others the traditional methods of access needed to remain in place.
	  ○ Some practices may already be at the upper limit of what proportion of digital access is offered and required.
	  ○ The new modern general practice model will enable those preferences to be articulated and addressed at the point of triage.
	  ○ There were no plans for a shift to 100% digital access.
	  ○ Data from advanced telephony could be used more analytically to understand the flow of demand across a day or a geographical area.
	  ○ Targets would not be imposed on individual practices.
	  ○ Further standardised of digital pathways was needed, should patients be using NHS App or Patient Access for example.
	  ○ Community pharmacy was not as advanced as general practice in terms of data and integration, the same principles for GPs should be applied to pharmacy to support digitalisation. 70% of pharmacies in Hertfordshire are independents who need support.
	  ○ Digitalisation served the “worried well” more than other cohorts and would not increase engagement from those hard-to-reach communities.
	• The opportunity of reducing bureaucracy within general practice and between general practice and other community services/providers should be fully explored.
	• The role of the voluntary sector had been integrated in the plan and could provide meaningful insights on the barriers/challenges that patients faced re digital access.
	• There was a need for a universal platform to list all community health services/voluntary services to which patients could be referred by either general practice or community pharmacists.
	• Q What did the data show re misdiagnosis and missed diagnosis because of telephone consultations? Ans: This had been reviewed nationally through RCGP and also experience from our local trusts is not indicating any adverse effect on diagnosis.
	•

	• The chair noted that no single access model was perfect, and any learning/significant event would always be reviewed and used as a learning opportunity to change/improve practice. Individual cases of misdiagnosis did not invalidate the pathway. • EHJ reported that there was no correlation between the method of access and misdiagnosis or missed diagnosis. • Access to Diagnostics within primary care would be the next area to be reviewed in terms of digital access, there would be more videos/photos used to inform triage. • Some practices had abandoned video triage, but AI might transform this area. • It was noted that within Children's Services, video consultations worked well as this offered families more flexibility.

52.3	Primary Care Strategic Delivery Plan
	James Gleed (JG) introduced the primary care strategic delivery plan (see pages 60-95 of the document pack) highlighting the following points:
	• The draft delivery plan had been shared at previous PCB meetings and was now in its final iteration.
	• There had been a high level of engagement with stakeholders and refinements made following comments and feedback; these themes had included:
	  ○ Lack of information about funding/pump priming; new sections had been added.
	  ○ Missing information about dentistry, optometry and pharmacy; this had been inevitable due to the timing of these services moving to PC but this section had now been expanded and would continue to be developed.
	  ○ Lack of specific information relating to enabling workstreams; this section had been overhauled and updated.
	  ○ Prevention section could be expanded; this has now been done with clarity provided on the role of healthy lifestyles/proactive care.
	  ○ Greater emphasis on the need for improved access for non-urgent needs.
	  ○ A new opening page from all primary care partners to provide context and the background for the plan.
	  ○ Better descriptions as to how the plan links and is aligned to other plans within the ICS footprint.
	• Proposed new funding 2023/24 (page 94):
	  ○ £3m: development of INT which includes the £1M into PCNs as agreed through national contract.
	  ○ £1.2m: on the day access with the highest need integrating with system provision.
	  ○ £1m PC digital deliverables including training and support
	  ○ £200,000: prevention and health inequalities working with Voluntary Care Sector through the wider work on inequalities under the personalised agenda
	  ○ £40,000: ongoing communication and patient participation and engagement work building on the work through Healthwatch and National Patient Association and local communications team

52.4	Questions and comments were invited: • Was a distinction needed between the role of social prescribing to support a younger person vs elderly citizen. Many young people did not engage with GP services. • AS noted that a team of children's social prescribers could be appointed to address this through primary care networks. • The three year long term plan which accompanied the delivery plan was welcomed. This would help Healthwatch with their planning for example. • Neil Tester shared some of the feedback Healthwatch were receiving on the impact of the cost-of-living crisis on families e.g. rationalisation medicines – this might require the up-skilling of clinical and non-clinical staff to better support families facing difficult choices. • AS noted, that issues raised in the cost-of-living report could be reviewed and included in the delivery plan based on priorities and how this support from the health and care side.

	• It was noted that it was not the role of primary care to solve poverty but to identify what areas it could influence policymakers, e.g. lobby nationally for cheaper medicines (buy one get one free for example). • The amount for prevention and health inequalities was reasonable small and could only achieve so much; recent Citizen Advice reports had highlighted the links between health poverty, housing and mental health – CA could provide many case studies describing the barriers these citizens faced.
52.5	**The PCB approved the Primary Care Digital Priorities and approved the Primary Care Delivery Plan** **AS to pick up further discussion with CA and JM on enhancing the role of the voluntary sector to support the patients in the community.**
PCB/53/23	**Primary Care Contracts Update**

53.1	**Progress on Access Recovery Plan**
	Andrew Tarry (AT) introduced this report (see pages 96-118 of the document pack) highlighting the following points:
	• The national plan had been released in May. This had included some new aspects which had been incorporated but mostly reinforced existing aspects of the plan.
	• Further detail on pharmacy first would be published later in the year.
	• Main tasks:
	  ○ Reduce silo working practice.
	  ○ Bring together ongoing work re access improvements.
	  ○ Move to the modern general practice model.
	  ○ Meet patient need.
	  ○ Reduce bureaucracy.
	• PCNs were working on access improvement plans (deadline 30 June) with a focus on triage and identifying patient need at first contact. These have been collated and are in the process of being refined.
	• Enhanced telephony: There were still 28 practices who operated on analogue systems. A new telephone system was not the panacea to access but would certainly help patient experience and improve data analysis. This was a national ask under the GP improvement programme.
	• £900,000 would be made available to support these practices move to cloud-based systems.
	• Further funding has been announced to support the transition from the old appointments system to a new appointments system.
	• See page 115 re plans for reducing bureaucracy between primary and secondary care. See page 116 re self-referral pathways to empower patients.

53.2	Questions and comments were invited: • The rate of change and challenge facing primary care was huge, it was good to see the support measures in place for practices. • Comms to GPs re the GP Improvement Programme has been high – but this had taken a lot of time and capacity to respond to – could this be more closely targeted to those practices who needed the support? • Q Was the funding allocation to support practices move to cloud-based telephony systems a good use of public money? Annual running costs of infrastructure should be self-funded by the practice. • Some practices needed support in better understanding the positive role the PPG could play; the PPG should be seen as an asset.
53.3	**Update on Dental Workplan and Procurement Plan** Rachel Halksworth (RH) introduced the dental workplan and procurement plan (see pages 119-127 of the document pack) highlighting the following points: • Responsibility for dental procurement had been taken on from 1 April. • 48 contracts inherited in April were due to expire in early 2024 and required urgent attention. Some would be extended. • Areas of priority: out of hours and on the day access.

	• Attention would turn to minor oral surgery and peri-dental in 2024 and baseline reports would be prepared in the autumn. • The procurement plan was in its first iteration and would be brought back to the committee for further scrutiny and discussion. • There was disparity between the two community specialist dental services, Hertfordshire did not have a service for anxious children for example. • Collaboration with local authorities was ongoing re oral health promotion and prevention. • The public health teams were mapping services across HWE and plotting this against geographical areas of need. This would be key for future procurement decisions. • Work was commencing with the University of Essex re workforce capacity, e.g. training non-dental staff to provide some dental services.
53.4	Questions and comments were invited: • The board were pleased that the team was now able to get into the detail of this area of commissioning. Was there a high enough focus on children's services within dentistry? Ans: Oral health promotion was focused on children. The disparity between services for anxious children in Herts vs Essex was noted. Many anxious children were referred to acute services for anaesthetic treatment, this was not a very cost effective or compassionate pathway. • A report on oral health had been commissioned across HWE. • Q How would the lack of capacity within dentistry be addressed? Further analysis of capacity hot spots/gaps was needed as overall, the dentistry budget was often underspent because activity was not delivered. • It was noted that the national contract was not very attractive to dentists compared to private work. The whole provision needed to be reconsidered as it would not be possible simply to raise the payment rates.
53.5	**The Primary Care Board noted the Primary Care Contracts Update**
PCB/54/23	**Update from Healthwatch**
54.1	Neil Tester introduced this agenda item on behalf of both Healthwatch Hertfordshire and Healthwatch Essex (see pages 128-254 of the document pack) which covered their completed reports on: a. Adults with learning disabilities' experiences of accessing GP services and support in living a healthy lifestyle; and b. Public understanding on cardiovascular disease, and self-management. The following highlights were shared: • Both sets of reports had been shared in draft at the May meeting and the adults with learning disabilities findings had been discussed in detail. • The teams were working on how best to frame their recommendations for the PCB so that the richness and narrative of the reports were converted into action.
54.2	Questions and comments were invited: • It was suggested that the reports should be first shared with primary care providers so that when it was submitted to the PCB for review it could be a dual presentation of report and recommended action plan. • This process could allow for input in from PPG and PCNs as well as messages out from ICB. • The quality and content of the reports was appreciated, and all partners needed to be mindful of the cost-of-living crisis and how this affected patient engagement; service delivery models should constantly be reviewed and considered through this lens. • As healthcare partnerships developed, a more rounded response would be possible with input from community and acute providers. • AS reiterated the ICB's commitment to funding the research undertaken by Healthwatch.

	• The agency and advocacy of the voluntary sector was highlighted; the ICB should start thinking about different service design in recognition of the work that the voluntary sector was already doing, their knowledge of patient experience was vast. • PPG also had a key role to play, although the engagement of PPGs across HWE was not yet consistent, with some areas struggling to find volunteers to join. • Innovative examples used by other practices were shared, eg, text message direct to individuals inviting them to volunteer in some capacity at the practice/local community. • COPD: different cohorts were more comfortable visiting their local pharmacy than their GP. • COPD was a priority area for the ICB; synergies were possible with the long-term conditions group who would have oversight of the work and initiatives underway by community partners. • The recommendations in the papers should include connections with the Long Term Conditions Group.
54.3	**The PCB noted the findings of Healthwatch Hertfordshire and Healthwatch West Essex**
PCB/55/23	**Patient Communication and Engagement Report**
55.1	Heather Eardley (HE) presented this agenda item (see pages 255-259 of the document pack) and highlighted the following points: • Support had been given to practice managers to help reinvigorate these groups. There needed to be mutual benefits for both patients and practices.
55.2	Questions and comments were invited: • The trajectory of work was good with almost 50% of practices now engaged. • The team were targeting those practices which had not yet responded. • Support was available online offering templates, tools, workshops etc these promoted the benefits to a practice that a PPG could offer. • Engagement by the public was strong but patchy; a recent healthy living event organised by a PCN was attended by over 600 people.
55.3	**The Primary Care Board noted the Patient Comms and Engagement Report**
PCB/56/23	**Reports/minutes from sub-groups**
56.1	The following reports were noted for information: • Primary care digital (pages 260-265 of the document pack) • Primary care workforce (pages 266-269 of the document pack)
PCB/57/23	**Reflections and feedback from the meeting**
57.1	• Today's agenda seemed less crowded which left more time for meaningful discussion. • Consideration might be given to breaking down targets and plans into short term and medium-term goals to better track progress. • New members would welcome a glossary of terms.
PCB/58/23	**Date and Time of next meeting**
58.1	Thursday 28 September 2023, at 9.30am
The meeting closed at 12pm	

Hertfordshire and West Essex Integrated Care System

NHS Hertfordshire and West Essex Integrated Care Board

Herts and West Essex Integrated Care Board PRIMARY CARE BOARD Action Tracker Last updated on 21 Sept 2023

Private / Public	Action Tracker Ref No	Date of Meeting	Subject	Action	Responsible Lead	Deadline Date	Comments and Updates	Status
Public	PCB/51.3/23	27/07/2023	Directorate Highlight Report	Consider how data can be presented to show impact	A Shah	**28/09/2023**		**Open**
Public	PCB52.5	17/07/2023	Primary Care Digital Priorities	Pick up further discussions with CA/JM on enhancing the role of the voluntary sector to support the patients in the community	A Shah	**28/09/2023**		**Open**

RAG Rating Key:	
Red	Open (overdue)
Amber	Open (on-going)
Green	Completed / Action Closed

Hertfordshire and West Essex Integrated Care System

NHS Hertfordshire and West Essex Integrated Care Board

Meeting:	*Meeting in public*	☒	*Meeting in private (confidential)*	☐			
	NHS HWE ICB Primary Care Board meeting held in Public				**Meeting Date:**	**28/09/2023**	
Report Title:	**Primary Care Transformation– Directorate Report**				**Agenda Item:**	**06**	
Report Author(s):	Updates incorporated from various leads across Primary Care Avni Shah Director Primary Care Transformation						
Report Presented by:	Avni Shah Director Primary Care Transformation						
Report Signed off by:	Avni Shah Director Primary Care Transformation						
Purpose:	**Approval / Decision**	☐	**Assurance**	☐	**Discussion**	☒	**Information** ☒
Which Strategic Objectives are relevant to this report **[Please list]**	▪ Increase healthy life expectancy, and reduce inequality ▪ Give every child the best start in life ▪ Improve access to health and care services ▪ Increase the numbers of citizens taking steps to improve their wellbeing ▪ Achieve a balanced financial position annually						
Key questions for the ICB Board / Committee:	N/A						
Report History:	N/A						
Executive Summary:	Highlight Report provides a brief overview on the progress since last board meeting with a view of not duplicating areas of discussion on the agenda and to give a flavour of the forward look of some of the key areas of focus.						
Recommendations:	The Board is asked to ▪ Note and discuss the key contents of the report.						
Potential Conflicts of Interest:	***Indirect***	☐	***Non-Financial Professional***	☐			
	Financial	☐	***Non-Financial Personal***	☐			

	None identified	☐
	N/A	
Implications / Impact: N/A		
Patient Safety:	*N/A*	
Risk: *Link to Risk Register*	*N/A*	
Financial Implications:	*N/A*	
Impact Assessments: *(Completed and attached)*	***Equality Impact Assessment:***	N/A
	Quality Impact Assessment:	N/A
	Data Protection Impact Assessment:	N/A

Hertfordshire and West Essex Integrated Care System

NHS
Hertfordshire and West Essex
Integrated Care Board

Primary Care Transformation– Directorate Report

Avni Shah, Director of Primary Care Transformation

Working together
for a healthier future

Vaccinations Update

Winter Vaccination

- Due to a new variant, the covid and flu programmes have been brought forward with commencement on 11th September for care homes (residents & staff) and at risk, with all other cohorts coming on line from 18th September. As in previous years HWE will include vulnerable cohorts including Severe Mental Health and Learning Disabilities.
- In light of this the funding has been reviewed and additional accelerated payment proposed with a view to prioritise certain cohorts to be immunised latest by end of October.
- Delivery models across HWE is via Primary Care Networks (PCNs), Community pharmacies and targeted outreach support delivered through Hertfordshire Community Trust.
- Co-administration will be encouraged where possible for care homes as well as for other cohorts, recognising some patients will not want both at the same time or that some are unable to have both at the same time.

Progress to Date

- As of 19th September, HWE had recorded 19,906 autumn booster doses
- HWE now has 144 sites offering covid vaccinations, as per below. Hospital hubs are also vaccinating their staff.

	Pharmacies	PCN sites
ENH	43	12
SWH	54	12
WE	17	6
Total	114	30

- HCT are assisting with roving models in areas of low uptake such as Hemel and Loughton, and care home and housebound for most of Dacorum PCNs which are opted out.
- PCNs are currently vaccinating Care homes and housebound patients, and offering covid during pre-planned flu clinics. 112 out of 313 care home visits are booked as of 15th Sep, and 28 of these have already been visited once. We are expecting more updates this week for the remaining homes.

Immunosuppressed Research Project

- As outlined previously we are funded through region to conduct a study to further understand what prevents at risk and/or immunosuppressed patients coming forward for a Covid vaccination. This research led by Public Health in Hertfordshire County Council has shown three main barriers:
- beliefs about change (if I get the booster how likely with if be effective and protect me);
- beliefs about consequences (low perception of risk of Covid 19);
- location (need for more local sites to access more easily).

Team have developed a set of recommendations some which are in trail and others will be to support future Spring or Winter vaccination programme.

- development of a FAQ document with invite;
- offering webinars;
- offering a booster when a patient attends other appropriate clinics for their condition
- Availability in easily accessible places including local schools and churches

There were also two recommendations that will be fed up to national level which includes how we can including a blood test to show current immunity levels when blood is being taken for something else to monitor the patients condition; and the use Qcovid risk tool to give patients a personalised risk score. This research will be used to support plans in HWE for the Spring 24 programme.

Winter

Whilst there is no additional national funding for winter pressures this year specifically aligned to Primary Care, acknowledging the national recovering plans and the system wide responsibilities to deliver a resilient winter, we have continued with local primary care funding to commission additional activity in primary care at the same level as last year, £1.43 per weighted patient, which will be subject to a PCN plan being appropriate to meet the local and national priorities. This capacity should support surges in practices in PCNs when reaching OPEL 3 or 4.

The key focus areas to consider are:-

- **Partnership working** - We are asking practices/PCNs to provide additional capacity while considering how that funding can be best used to meet the needs of local population e.g. additional same day access hub working/appointments to ensure planned care is maintained, or extension of enhanced access provision to support planned care whilst all other appointments become same day. Considering working more closely with system partners e.g., more direct bookings from 111 triage, integrating with community partners including rapid response/prevention of admission or local community pharmacies to support enhanced care for minor ailments.

- **Same day access hubs** - Learning from the evaluation of respiratory hubs in 22/23, to be truly effective, these need to be embedded at PCN level or locality within core, enhanced access and additional capacity, and to cover the full range of potential presenting symptoms to be able to respond to any surge in demand, not respiratory alone, and to cover all ages, not adults alone. We are keen for PCNs to design their model for managing surges in demand, locally, based on local data and knowledge.

- **Phasing** - The funding can be utilised between 1st October 2023 and 31st March 2024; however, we would suggest practices/PCNs consider whether they wish to phase the capacity over the 6 months or retain some capacity to manage unexpected surges in demand during the winter. The capacity can be used in a hybrid approach between practices and same day access hubs, again phased during the 6mths, e.g., hub only operating at peak times.

- **Workforce** - To maximise the funding available, PCNs should also consider how existing and additional appointed workforce for winter support the winter demands.

Each PCNs is currently submitting their plans to the ICB

Winter – Ongoing Industrial Action

Industrial Action Support

A pilot was agreed to identify suitable support, by the ICB, to Primary Care, the aim of the pilot is to test support for possible events by creating additional appointments in general practice that were available for ‘on the day access’ for patients clinically requiring services. A single payment was given to each PCN to mobilise additional workforce to;

- Help maximise clinical support during Industrial Action in the community and avoid patients unnecessarily attending acute hospital, where the worst impact of industrial action was evident.

- Demonstrate if this would work as an offer of support to practices that report OPEL levels 4.

Analysis is still ongoing in terms of the impact it has shown for industrial action and currently working through OPEL reporting and action cards to ensure a consistent approach by all practices, so that any offer of support is fair and proportionate.

Primary Care Contracting – Primary Medical Services

As outlined in the approved Primary Care Strategic Delivery Plan, we will be looking at way of innovative but sustainable primary care contracting of services.

Some of the key updates since last Board meeting include:

- APMS contract award to Stellar Healthcare (GP Federation in West Essex) for the provision of primary care services to Jacobs and Gardens Neurological Rehabilitation Centre in Sawbridgeworth. This is a specialist care home and aim of this contract award is to provide the resilient and long term support over 3 plus 2 year contract working closely with community and care home provider. The provider commenced provision of services from 1 September 2023.
- The procurement of the APMS Contract at Spring House Medical Centre concluded and following the 10-day standstill period, with no challenges, the ICB were able to award the contract to the successful bidder; Ephedra Healthcare Ltd who are the incumbent provider. Instead of the standard 3 year contract, this transformational contract has been agreed for 10 years which was approved by NHSE in line with the Delegation Authority.

Primary Care Contracting – Community Pharmacy and Optometry

The Pharmacy and Optometry Team (P&O) have been successfully embedded into HWE as of 1 April 2023.

As outlined previously as of July 2023 HWE as host is responsible for **market entry and Fitness processes for Pharmacy, the latter** which has transferred from Professional Standards Team at NHSE. NOTE HWE hosts this function across East of England on behalf of the other ICBs.

To support the fitness processes, HWE vacancy panel approved the transfer of the pharmaceutical and optometry clinical from NHSE to HWE who provide support to this process including as case reviewers, providing clinical input in contractual initial and follow up visits with the contracting team. Note this was not a TUPE transfer for these clinical advisors as they will work ad hoc under a contract for service.

The P&O team under the governance of Pharmaceutical Service Regulations Committee have undertaken a review of the processes to develop a Standard Operating Procedure for Fitness and will continue to refine this with the learning to date.

The Memorandum of Understanding between HWE and the rest of ICBs has been reviewed with suggested amendments to the appendices made in draft to reflect some of the complexity and interdependence, including matters arising as we learn from the process such as engaging legal support and the role of each ICB at appeals, linking with each ICB whistleblowing, freedom to speak and complaints processes etc.

Teams are working closely with NHSE Professional Standards team to clear the backlog of fitness matters whilst having taken on the new ones from July 2023 and follow through with the ones through appeal.

Primary Care Workforce Update

HWE Primary Care Careers Fair 2023

- The HWE primary care careers fair will take place on 21 September 2023, 10:00 – 14:00 pm at The Fielder Centre, Hatfield, Hertfordshire.
- The event will be set up with a main area market place with a selection of stalls all day promoting various careers in Primary Care.
- There will be the option of one to one support with CV/interview skills and various careers talks ie Apprenticeship programmes, Allied Health Professional describing their journey in Primary Care, non clinical roles and Herts and West Essex as a place to live and work.
- Over 100 people have booked to attend the event. The event is also a walk in event.

Enhanced GP Fellowship Programme

- Building on the success of the previous years scheme, the Enhanced GP Fellowship programme has been launched.To date we have already had 19 expressions of interest.
- A number of specialist areas are being sort, they are Hertfordshire Community Trust, Hospital @ Home, Chronic Fatigue/long covid, Childrens Mental Health. Central London Community Health Care Trust – care of the elderly, rapid response, long covid, frailty, sexual health. Princess Alexandra Hospital – Womens health, emergency medicine, cardiology, and dermatology. Discussions in place with East and North Herts Hospital Trust and West Herts Hospital Trust.
- Teams are working closely with the Medical Directorate in order to ensure there is a joined up approach and we prioritise as outlined in the clinical areas. Evidence from previous year has indicates 85% of the GPs who enrolled in the programme are currently still practicing across HWE ICB as a GP showing good retention and some also continuing to enhanced work in the specialist area part time.

Primary Care Workforce Update

Primary Care Awards – HWE Celebrating Primary Care Achievements 2023

The awards ceremony will take place virtually on Wednesday 11 October 2023, 7:00 – 8:30 pm.
Nominations have been received for all categories. In total 79 nominations received. The aim of this is to celebrate and learn from good practice, share it across the system for it to be adopted.

Award	Nominations received - Totals
Digital Transformation	7
Excellence in Patient Engagement	9
Excellence in Supporting Staff Health and Wellbeing	5
Excellence in Training and Development	17
Integration and Collaboration	8
Leaders in Innovation	6
The HWE Community Pharmacy of the Year 2023	4
The HWE Dental Practice of the Year 2023	2
The HWE General Practice of the Year	3
The HWE Ophthalmic Service of the Year 2023	3
The HWE Primary Care Network of the Year 2023	8
The HWE Team of the Year	7
Grand Total	79

Primary Care Workforce Update -

Community Pharmacy Independent Prescribing Pathfinder Programme update

- From 2026 updated training standards will ensure all newly qualified pharmacists are independent prescribers
- HWE ICB has been successful to implement this programme across 5 pilot sites across our system.
- EPS licenses for a web-based standalone solution will be provided for all Pathfinder sites (procurement is underway – timescales to be confirmed)
- Condition of the funding allocation is that the EPS nationally procured solution will be the only one funded by the programme.
- Access to GP patient records will be via Community pharmacy IT clinical systems in the community pharmacy using GP Connect
- Access to local shared records and pathology services will need to be identified locally and any associated costs identified to regions to seek approval for any additional funding requirements that are critical to the clinical pathway and patient safety.

Primary Care Access – High level update

- All 34 PCNs have an agreed Access Improvement Plan as outlined in the Primary Care Access Recovery Plan.
- Practices are implementing the areas of development and actions in the plan including some practices transitioning to Modern General Practice through understanding of their ever-changing demand and capacity, maximising the use of cloud base telephony where in place, enrolling for the National GP Improvement Programme (19 practices and 4 PCNs), roll out NHS app, online GP registration, development of GP and PCN websites and testing triage models.
- Over 20 sites have been identified for the roll out of cloud base telephony which was approved in July 2023. However, delays in implementation via the national procurement hub which may result in these practices unable to show a change and improvement in telephone access for 2023/24. This has been escalated to the regional team.
- Good progress being made on online access to GP records. Targeted work with 29 practices to enable access by opting into (EMIS) or following self-enablement process (TPP).
- In addition progress being made through partnership working at interface meetings to cut bureaucracy and how we increase self-referrals in number of high volume services such as access to physiotherapy, IAPT, podiatry etc.
- Each system to develop an overarching System plan outlining progress against each area. ICB assurance meetings on delivery on primary care are now set quarterly with NHSE

Hertfordshire and West Essex Integrated Care System

NHS
Hertfordshire and West Essex
Integrated Care Board

Learning Disability and Autism Update

September 2023

Working together
for a healthier future

Learning Disability and Health Inequalities

- Numerous reports over the last 15 years evidence that people with a Learning Disability die significantly younger than the general population and are more likely to die from preventable conditions. They are more likely to have multimorbidity from a younger age and greater complexity.

- There is also evidence that Autistic people die earlier than the general population and are at increased risk of co-morbidities such as diabetes and cancer.

- From the recent LeDeR Report 2022-23, for people with a Learning Disability the median age of death in Hertfordshire is 61; more than 20 years younger than the general population. The most frequently reported ICD-10 chapter for underlying causes of death remains consistent with previous years; namely, disorders of the respiratory system, neoplasms/cancer and diseases of the circulatory system. Most noted leading causes of death include lower respiratory tract infections (n=6), pneumonitis due to food and vomit (n=5) and sepsis (n=5).

- More recently our report on lived experience of citizens with Learning Disability across Hertfordshire and west Essex outlined proposed a number of recommendations for the ICB to consider and action as appropriate. A number of those have been taken on board and progress update provided.

- Addressing Health Inequalities through key workstreams in Primary Care
    - Annual Health checks and quality health action plans
    - Access to immunisations and national screening programmes
    - Improving access to health care through knowledge of Reasonable Adjustments
    - Training – raising awareness of Learning Disability and Autism
    - Feedback from patients, carers, families.

Engagement with Adults with Learning Disabilities: Healthwatch Hertfordshire & Essex

Key Findings:

Access

- Long delays when contacting by telephone and difficulties in getting an appointment. For some, this has made them reluctant to contact their GP practice unless their concern is urgent.
- Difficulty contacting their GP practice during opening hours as this is outside their support worker's working hours.
- Difficulty communicating with receptionists and treated poorly.
- Care Coordinators are GP practices provide invaluable support.

Choice

- Face-to-face is preferred, with many finding telephone and/or video appointments inaccessible.
- Seeing the same GP or nurse is very important. However, respondents have to wait several weeks to see the clinician of their choice.
- Lack of flexibility around appointment dates and times which respondents find difficult to work around their own schedule and their support worker's working hours.

Communication

- Clinicians and receptionists can speak too quickly and use complicated language.
- Information is often not provided in Easy Read.
- Some respondents had very positive experiences, emphasising that clinicians are kind, helpful and accommodating.
- Clinicians can speak to carers and support workers, rather than addressing respondents directly which respondents find upsetting and disrespectful.

Healthy lifestyle

- Clinicians have discussed healthy eating and exercise with respondents. However, they would like more regular conversations about this, as well as more practical support and information.
- Clinicians were less likely to have discussed mental health, social life, drugs and alcohol, smoking and sexual health. Although some of these issues were not important to most respondents.
- Cancer screenings need to be discussed more, with most respondents lacking awareness about what they are and why they are important.

Annual Health Checks

- Some had a very positive experience, receiving a thorough examination of their physical and mental health.
- Some had a more negative experience, only receiving a short appointment and a basic examination.
- A few respondents have never been offered an Annual Health Check or have not been contacted about their Annual Health Check for a couple of years.

Learning Disability Update

- **LD Annual Health Check (AHC)**
  - Building on the success of achieving our target for LD Healthchecks as an ICB for 2022/23 we are proactive in reviewing data regularly and continuously improving. NHSE data for June 2023 shows that for HWE 9.9% of LD AHCs have been completed, but only 8.6% of Health Action Plans (HAP) have been made. Noting a difference of 112 less AHC completed this year, compared to the same time last year.

Place	% Completed Health Checks end June 2023	% Health Action Plans end June 2023	% Completed Health Checks end June 2022
East and North Herts	**11.1%**	9.7%	13.4%
West Herts	**8.3%**	7.4%	9.9%
West Essex	**11.4%**	8.9%	11.5%

  - To understand the difference in delivery LD nurses in Hertfordshire have contacted all practices where a large difference was noted in the number of LD AHCs completed, between May 22 and May 23. Reports from practices include that they have changed the way that they are inviting patients (changing to birth month) or have had a slow start due to workforce staffing issues with continuous rising demands.
  - **Data accuracy** – In May 2023 NHSE informed that some ICBs in the region have identified discrepancies between the National LD AHC Data and their local data reports. Reviewing local data reports for HWE only 1 practice has been confirmed as being affected – AHC booked via PCN hub, data not extracted via GPES, awaiting guidance from NHSE how to resolve.
    - This is a large practice (303 LD patients aged 14+), but very proactive and engaged with LD AHC and LD nurses. They have completed 89 AHCs (compared to 3 on the national data), which alone would bring the difference in AHC completed down to 26, rather than 112 as above.
  - **Ardens template updated** – includes codes required for IIF and ECF and links to local resources for both Hertfordshire and West Essex. This will support recommendation from Healthwatch findings on ensuring it is a comprehensive and appropriate physical health check linked with various areas including screening and healthy lifestyle information and signposting as appropriate
  - **Health Action Plans (HAP)** – raising awareness via Community LD nurses and LD Update Bulletins. Those practices with a large difference in the number of AHC and HAP completed in Hertfordshire and West Essex have been contacted to understand the reasons for this and provide support – whether in coding or completion of the HAP.

Learning Disability Update

- **Vaccinations –** Patients with LD are eligible for Flu and Autumn COVID Booster– LD Bulletin and Community LD nurses are raising awareness of the importance of vaccinations, Reasonable Adjustments, preventing barriers to accessing the vaccines, support for those patients that decline or need more than reasonable adjustments, raising awareness of capacity and BI decisions.

- **Health passports –** Purple folder updated in Hertfordshire following feedback from health professional across Hertfordshire. My Health Information Document also produced for CYP aged between 11 and 17 years. The health passports provide professionals with essential information regarding recent medical appointments and reasonable adjustments required. Also, information on the person's baseline communication, appearance and behaviour to aid recognition of any changes to reduce diagnostic overshadowing.

    - Purple folder - https://www.hertfordshire.gov.uk/services/adult-social-services/disability/learning-disabilities/my-health/professionals/information-for-professionals.aspx

    - My health information document - https://www.hertfordshire.gov.uk/microsites/local-offer/preparing-for-adulthood/health/health.aspx

- **Transition** – from LeDeR reviews any transition can be a high-risk period. This includes:

    - **Transition to adulthood -** Resources have been reproduced to support this time - Preparing for Healthy Adulthood Guide and 6 short videos sharing practical advice for patients and parents/carers - https://www.hertfordshire.gov.uk/microsites/local-offer/media-library/documents/preparing-for-a-healthy-adulthood-final.pdf

    - **Discharges from Hospital** – works is ongoing with Safeguarding teams within the Acute Trusts and Adult Health liaison Teams to improve the quality for discharges, including an Easy read discharge booklet.

    - **Transition to new care settings** – work to review the process for moves and gain assurances robust pathway for those with complexity.

- **Screening/STOMP –** In Hertfordshire Health Equality Nurses focus on improving access to cancer screening. There is also a STOMP nurse to support the National STOMP programme. A Community LD Meeting is held every 2 months with Community LD Nurse Leads and Clinical LD Leads from Hertfordshire and West Essex to share practice and learning.

Learning Disability Update
Reasonable Adjustment Digital Flag

- Hertfordshire is an early adopter site for the Reasonable Adjustment Digital Flag.
- Raising awareness amongst professionals and patients/carers – ECF, HCT White board Amination - https://www.hwetrainghub.org.uk/resources2/reasonable-adjustments-learning-disability-and-autism-training-resources.
    - We have seen greater understanding of reasonable adjustments, greater use of reasonable adjustments, especially in delivery of vaccinations, and greater use of coding.
- NHSE will release an Information Standard and Guidance in Autumn. ISN will go to all Health and Social care services, will cover children and adults and everyone requiring Reasonable Adjustments as per Equality Act 2010.
- Equality Act 2010 – Disabled "if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities".
- ISN will start with Learning Disability and Autism first.
- Phase 1 – Local – Identify patients and ask about Reasonable Adjustments
    - Identify, Record, Flag, Share, Meet need, Review
    - Good progress in HWE through ECF for Learning disability. Work will be required for Autism.
- Phase 2 – What we know, everyone should know - API being developed to enable information to be shared – get/write
- NHSE are developing training – aimed to be available Q1 24/25

Continuous improvement in Access – work is underway through access improvement plan to continue supporting practices to move to advance cloud based telephony; ensure learning disability have additional information on how to make appointment and the choice of appointments available.

Learning Disability Update
Training

- **Oliver McGowan Mandatory Training (OMMT) -** Training in Learning Disability and Autism, appropriate to role, is a requirement as per the Health and Care Act 2022. The Oliver McGowan Mandatory Training is not mandatory but is the Government's preferred and recommended training for health and social care staff. The ICB are supporting the OMMT and are working with teams across the system to ensure local initiatives are included in the training also. HCPA are supporting the roll out.
    - Work to link up with the Purple Star Training (Hertfordshire Primary Care) that is already in place to avoid duplication of process – current pilot in Hertfordshire with 2 PCNs.
    - August update from HCPA - over the past few months, the priority has been to get experts with lived experience in place. There are now 7 in place; people with autism and with a LD (applications remain open). There are currently offering courses available to anyone/any organisation or direct training where training is offered to an organisation. Courses available since august 2023, being run at HCPA.
    - The first train the trainer cohort takes place in September 2023.
- **Additional Primary Care Training** – Community LD nurses are in conversation with the Training Hub have hosted webinar and continue to provide training at PCN training sessions. This would offer those key to delivering LD care within practices the opportunity to attend a training session once a month– a lunchtime and evening webinar will be offered, both for Hertfordshire and West Essex practices, and a twice-yearly face to face session. Encouraging each practice to have a Learning Disability Champion which has been submitted. Aim is now how this is publicised through practice website and others so that patients are aware.

Learning Disability Update
Continuous Feedback

- Ask, Listen, Do – National Programme aimed at **improving experiences and outcomes for children and adults who are autistic or have a learning disability, their families and carers**
- Ask Listen Do resources are designed to:
    - Support organisations to listen, learn from and improve the experiences of children and adults who are autistic or have a learning disability, their families and carers
    - Make it easier for people, families and paid carers to give feedback, raise concerns and complain.
- How can we support Primary Care embed Ask, Listen, Do into practice?
    - The Community LD Nurses have produced an easy read feedback form for practices which could be put on websites with the Ask, Listen, Do ‘button’.
- **Healthwatch Feedback**
- **Ensuring flexibility, use of reasonable adjustments and learning from feedback in improving access to primary care plans, including triage models.**

Click here to fill in our Ask, Listen, Do form

Learning disability Pilots to tackle inequalities

- A pilot project to create a **pathway for prevention of aspiration pneumonia** began in 2023.
    - This was an extension of the Learning Disability Care Coordinator Pilot which was conducted in two PCNs (one in East and North Herts and one in West Herts) in 22/23.
    - Aspiration pneumonia remains one of the leading causes of death for people with a learning disability in Hertfordshire. Aspiration pneumonia risk factors include dysphagia, poor oral care, multiple medical diagnoses including poor posture. A new approach combining Dentists, Physiotherapists and Speech and language therapists working together with GPs to make a difference.
    - The Specialist Dental, Specialist Physiotherapy and Speech and Language Therapy services have held joint training sessions for GPs from the practices in the 2 PCNs to highlight the risk factors associated with aspiration pneumonia and raise awareness of the pathway.
    - A toolkit has also been developed to support GPs with referrals. Referrals are now being made from GP practices across two Primary Care Networks (PCNs) where risks are identified (usually at the AHC). The pilot is ongoing in 2023-24 and will be evaluated this year.
- HPFT have a **physiotherapy pilot** project to provide specialist assessment and intervention to support postural support and respiratory needs continued in 2022-23. The pilot has supported carers to implement interventions to minimise the risks associated with these conditions and ensure better overall health outcomes. Following positive outcomes from evaluation, there has been agreement to continue and expand this service.

Health Inequalities Project

- As part of the Personalised Care funding 66K was awarded to Herts and West Essex during 2022/23.
    - **PCN LD Care Coordination**
    - **Desensitisation pilot**

PCN LD Care Coordination - PCNs were offered a time-limited funding opportunity to help address health inequalities faced by this cohort of patients.

- This funding should support PCNs to identify and engage people with learning disabilities who face inequalities within this population; those aged 14-24, harder to reach – not responding to invites/calls, declining, those with obesity and those from a BAME background.
- £1500 was made available to each of the 32 PCNs in the region to:
    - Identify a nominated Learning Disability Champion/ Lead within the PCN to provider leadership to the project and act as the point of contact for support. GP Practices may share champion/lead across a PCN. The Lead may also act as the Care Coordinator but this could be a disaggregated role.
    - Use the funding to deliver activities in line with the proposed project, including:
        - Oversee LD annual health check process within the practice, linking with other GP practice, PCN or wider health and social care teams as appropriate to support delivery.
        - Implement any changes, as required, to effectively implement the national requirements for LD and local requirements.
        - Liaise with other practices and/or PCNs to share best practice.

Health Inequalities Project

PCN LD Care Coordination – cont.

- 10 PCNs responded with an EOI (31% of PCNs). Work started Q1 2023/24 and practices have utilised funding in different ways. Examples below:
  - Potter Bar PCN – 3 practices - using the funding to individually allocate care coordination work to target those hard to reach patients and offer home visits where required
  - North Watford PCN – using the funding for PCN manager time to oversee the AHCs – targeting harder to reach patients
  - Stevenage South – Using funding for greater coordination of AHCs across the PCN – practices moving to birth month approach, actively following up those that decline, liaising with LD nursing and joint home visits for hard to reach.
  - Hatfield PCN – using the funding across the PCN for coordination of the AHC, focusing on harder to reach patients, liaising with LD nursing for those who do not respond.
  - Herts Five - Allocated a PCN Care Coordinator to provider leadership to the project and support practices within the PCN with the delivery of the LD Annual Health Checks, understand any challenges/barriers and provide support/guidance to overcome these. Focusing on harder to reach and those aged 14-17 years.
- Will continue to collect feedback over the year to establish the value of LD care coordination to help address health inequalities within the LD population.

Desensitisation pilot

- Cohort of patients with learning disabilities who have never been able to have a blood test or vaccine due to needle phobia or behaviour which can challenge.
- HCT and Community LD nurses have created a pilot ‘More than Reasonable Adjustments’ which will worked to identify the least restrictive means to enable blood tests or vaccination. All practices across HWE able to access.

Questions

Hertfordshire and West Essex Integrated Care System

NHS Hertfordshire and West Essex Integrated Care Board

Meeting:	*Meeting in public*	☒	*Meeting in private (confidential)*	☐				
	NHS HWE ICB Primary Care Board meeting held in Public				**Meeting Date:**	**28/09/2023**		
Report Title:	**Primary Care Risk Register**				**Agenda Item:**	**07**		
Report Author(s):	Andrew Tarry, Head of Primary Care Commissioning							
Report Presented by:	Andrew Tarry, Head of Primary Care Commissioning							
Report Signed off by:	Avni Shah, Director of Primary Care Transformation							
Purpose:	**Approval / Decision**	☐	**Assurance**	☐	**Discussion**	☒	**Information**	☒
Which Strategic Objectives are relevant to this report **[Please list]**	• Increase healthy life expectancy, and reduce inequality • Give every child the best start in life • Improve access to health and care services • Achieve a balanced financial position annually							
Key questions for the ICB Board / Committee:	The Committee is asked to note the content of paper							
Report History:	A new Risk Register for the HWE ICB Primary Care Directorate has been created; this brings together and replaces risks previously recorded and tracked on individual CCG Risk Registers. Work commenced on this as part of the preparatory work for creation of the Hertfordshire and West Essex Integrated Care Board. The Risk Register was presented to the Primary Care Commissioning Committee in Common of the three Hertfordshire and West Essex CCGs in May 2022 and to the Herts and West Essex ICB Primary Care Board in August 2022. The risk register is a dynamic document and is presented to the Primary Care Board for review, discussion and information.							
Executive Summary:	Recognising that an update on the Primary Care Risk Register has not been provided to the last few Primary Care Board meetings, this is a brief update focusing largely on the ongoing and long-term risks previously identified. An update on Digital aligned risks revises 3 of the previous key risks highlighted from the previous Digital First Programme risks. In addition 2							

	further risks have been identified as crucial issues impacting the digital agenda at this time. Further review of the Digital environment and potential risks will be undertaken in the coming months by the Head of Primary Care Digital. Closure of two risks are proposed; those relating to the commencement of Enhanced Access services and the withdrawal of COVID-19 mass vaccination centres. Both were specific timebound risks where there have been subsequent developments, meaning these risks are no longer current or relevant. An update is provided on the risk related to the growth in the placement of Asylum seekers in local hotels. This reflects further national clarity obtained and the agreed local approach to mitigate the pressure on General Practice. Updates to existing risks have been included, where relevant, to reflect the key focus on the Delivery Plan for Recovering Access to Primary Care.			
Recommendations:	The Committee is asked to • Note the proposed changes to the risks that have been reviewed • Note the update and progress made			
Potential Conflicts of Interest:	***Indirect***	☐	***Non-Financial Professional***	☐
	Financial	☐	***Non-Financial Personal***	☐
	None identified			☒
Implications / Impact:				
Patient Safety:	Patient safety issues are recognised in the appropriate risks			
Risk: *Link to Risk Register*	NA			
Financial Implications:	NA			
Impact Assessments: *(Completed and attached)*	***Equality Impact Assessment:***	NA		
	Quality Impact Assessment:	NA		

	Data Protection Impact Assessment:	NA

1. Executive summary

Recognising that an update on the Primary Care Risk Register has not been provided to the last few Primary Care Board meetings, this is a brief update focusing largely on the ongoing and long-term risks previously identified.

An update on Digital aligned risks revises 3 of the previous key risks highlighted from the previous Digital First Programme risks. In addition 2 further risks have been identified as crucial issues impacting the digital agenda at this time. Further review of the Digital environment and potential risks will be undertaken in the coming months by the Head of Primary Care Digital.

Closure of two risks are proposed; those relating to the commencement of Enhanced Access services and the withdrawal of COVID-19 mass vaccination centres. Both were specific timebound risks where there have been subsequent developments, meaning these risks are no longer current or relevant.

An update is provided on the risk related to the growth in the placement of Asylum seekers in local hotels. This reflects further national clarity obtained and the agreed local approach to mitigate the pressure on General Practice.
Updates to existing risks have been included, where relevant, to reflect the key focus on the Delivery Plan for Recovering Access to Primary Care.

The risk register is a dynamic document and is presented to the Primary Care Board for discussion and information.

2. Background

Historically each of the three CCGs in HWE developed and maintained a primary care risk register; risks meeting predetermined thresholds were reported to Board.

Work commenced on a new consolidated risk register across HWE as part of preparations for the creation of the HWE ICB.

Each of the three individual risk registers have now been fully reviewed and archived as part of creating the new consolidated ICB risk register across the three ‘places’.

3. Issues

Recognising that an update on the Primary Care Risk Register has not been provided to the last few Primary Care Board meetings, this is a brief update focusing largely on the ongoing and long-term risks previously identified.

Workload pressures and the focus on key priorities, especially including assuming delegated responsibility for POD services and the national Delivery Plan for Recovering Access to Primary Care, have not allowed for a comprehensive review of Primary Care risks in the intervening period.

4. Actions

The following updates have been included:

Digital aligned risks
This update revises 3 of the previous key risks highlighted from the previous Digital First Programme risks, which were directly relevant to and potentially impact on Primary Care. In addition 2 further risks have been identified as crucial issues impacting the digital agenda at this time.
Further review of the Digital environment and potential risks will be undertaken in the coming months by the Head of Primary Care Digital.

POD Delegation risks
These 3 Primary Care specific risks related to POD delegation were included for the first time in March. These are reasonably high level risks bringing together key risks under the headings of Finance, TUPE implications and Quality. These were timebound risks highlighting some of the potential implications of the ICB assuming delegated responsibility for POD. Review.
Further review will be required to incorporate the key ongoing risks as part of the Primary Care Risk Register.

Proposed closure of risks
It is proposed to close the following risks:

- Risk PC12/331 regarding commencement of Extended/Enhanced Access (EA) services. EA was fully implemented from Oct-22 under the PCN DES.
- Risk 538 COVID-19 Mass vaccination centres – Autumn/Winter (AW) 2023-24 Flu and COVID-19 Seasonal Campaign details published; risk related to previous campaign & no longer relevant. Delivery models across HWE is via Primary Care

Networks (PCNs), Community pharmacies and targeted outreach support delivered through Hertfordshire Community Trust.

Other updates
Risk 617 related to the growth in the placement of Asylum seekers in local hotels; this risk has also been updated to reflect further national clarity obtained and the agreed local approach to mitigate the pressure on General practice.

Updates to existing risks have been included, where relevant, to reflect the key focus on the Delivery Plan for Recovering Access to Primary Care.

5. Resource implications

Capacity constraints in the Primary Care Contracting Team, further impacted by competing work priorities

6. Risks/Mitigation Measures

As noted above.

7. Recommendations

The Committee is asked to:

Note the changes to the risk register – new and existing risks.

Receive the risk register at future meetings (in accordance with the Primary Care Commissioning Committee's Annual Cycle of Business) in order to satisfy itself that risks are being appropriately captured and rated and that relevant/proportionate mitigation and controls are in place.

8. Next Steps

Ongoing review and update of the risk register.

Ensure that all recent updates to the risk register are entered onto the Datix system.

Work with other Directorates to ensure that key risks from relevant areas are shared with the Board in future updates.

Transition Risks

Risk Profile															Assurance Mapping							
ID	Datix ID	Date C	HWEK	Comm	Executi	Revise	CCG Risk Description	Rating	Rating	Rating	Risk M	Controls	Gaps in controls	1st Line Operational functions enforcing required behaviours and working	1st Line	2nd Line Oversight functions undertaking scrutiny and	2nd Line	3rd Line Functions providing independent and objective	3rd Level	Gaps in assurance	Approval status
PC1	318	10/11/2021	1 2 4	Primary Care Commissioning Committee	Director of Primary Care Transformation	ENH Head of PC Transformation	**IF** points of participation and influence for primary care in the new ICB and HCP structures are not made clear during the transitional period… **THEN** meaningful engagement with primary care may not be sustained into the new ICB arrangements… **RESULTING IN** challenges enacting ICB plans for delivery at place.	20	12	8	No movement ↔	1. Agreement of ICB governance structure 2. Oversight of previous CCG leadership roles in the initial transitionary period 3. Use all avenues to engage Primary Care, such as existing CD/Primary Care meetings 4.Appointment of key Primary Care roles 5. Embedding of Primary Care leadership roles & agreement of appropriate engagement fora 6. Sept 23 update - the ICB has an approved Primary Care Strategy in place following an extensive period of engagement with stakeholders and patients.	1. Further development of engagement fora & embedding of PC leadership roles. Clinical Leads induction event held. 2. Commencement of engagement in key ICP & ICB meetings requiring PC engagement (Sept 23 update - propose both gaps in control are deleted)	Primary Care SMT and wider team meetings. Primary Care attendance at place SMT meetings	Reasonable	Updates to the ICS Partnership Board, Health & Care Partnership Boards and Audit Committees.	Reasonable	Transformation assurance processes with NHSE	Reasonable	ICB and HCP structures fully implemented and embedded	The risk was approved for inclusion by Committees meeting in common, March 2022. Reviewed by PCB Sept-22 & agreed to risk score reduction from 20 to 12
PC2	320	10/11/2021	1 2 4	Primary Care Commissioning Committee	Director of Primary Care Transformation	ENH Head of PC Transformation	**IF** pressures in general practice remain at the current high level… **THEN** there may be insufficient capacity for GP practices, primary care networks and federations to deliver against transformation of care priorities in a way that demonstrates tangible improvements for patients… **RESULTING IN** sub-optimal patient experience due to continued pressures across the system and especially in acute services.	20	12	8	No movement ↔	1. ICB providing support to GP practices, PCNs and GP federations in planning for the transformation of delivery of care in Hertfordshire and West Essex. 2. Primary care teams have implemented the national GP Forward View transformational programme which includes extended access. 3. 'E-consultation' has been accelerated due to the pandemic and national and local initiatives are being implemented to develop practice telephony to deal with increased demand. 4. Organisational development programmes for PCN clinical directors and PCN managers are being supported. 5. PCN DES sign up: national requirement now met with all practices in a PCN, or non-participating practices covered by other PCNs as a local agreement. 6. Primary Care Input in ICS clinical strategy. 7. Training for Primary Care Networks to equip them to develop at pace in line with national requirements and for GP Federations to help them to understand their role in the development of PCNs. 8.Further ICB investment for PCNs to support training and implementation of services at PCN level, including additional workforce, training provision and backfill to attend. 9. Further training being identified to support GPFV/NHSLTP priorities. 10. Introduction of ICB wide ECF scheme, including Primary Care OPEL status reporting as part of the wider system reporting and improve understanding of pressure points for general practice. 11. Continue to support practices with IT infrastructure to mitigate the impact of workforce challenges with increasing numbers of primary care staff needing to work remotely and isolate. 12. Fora for regular engagement between ICB and PCN CDs, primary care and clinical leads in all 3 places 13. Dec-22 update - recognising significant winter pressures a review of ECF requirements was undertaken. A risk-based approach has been taken to prioritising key areas, balancing operational pressures (both within primary care and across the wider health system) with the health needs of the population. Aim is to ensure that practices will be able to release clinical capacity to better manage the increase in on the day demands. 14. ICB working collaboratively with PCNs & wider system providers to implement hub solutions to support increase in respiratory & other urgent on the day capability. 15. Feb-23 update - ICB QOF/IIF mitigation support offer made to all practices & PCNs 16. Sept-23 update - ICB has responded to the publication of the Primary Care Access Recovery Plan and is communicating and supporting PCN's with implementation 17. Sept-23 update - ICB is supporting Practices and PCNs to partcipate in the GP Improvement Programme (GPIP) 18. Sept 23 update - in response to the ongoing IA the ICB is supporting PCN's with increasing capacity to support system wide approach. 19. Sept 23 update - the ICB has undertaken a period of engagement and has an approved Primary Care Strategy in place to support integration of primary care and to support general practice.	1. Arrangements for appropriate primary care input at all key ICB and HCP meetings and sub groups have been agreed and being implemented (Sept 23 update - propose this gap in control is now deleted as already states that this input has been implemented) 2. Primary Care Strategy for the ICB being developed. (Sept 23 update - propose this gap in control is now deleted as added under controls Strategy is now approved)	• Primary Care Working Groups support the preparation and monitoring of plans with any risks or issues escalated. Risk registers monitor resilience in all practices. • Resilience panels receive applications for support • ICS population health management group. • Practices are compliant with national and regional guidance during the Covid 19 pandemic.	Reasonable	•Place based delivery boards have a strong primary care presence and monitor delivery against locality plans. • All overseen by the Primary Care Commissioning Committees and Primary Care Board and reported to ICB Boards as appropriate. •Primary Care updates and assurance papers to other ICB Committees and groups as appropriate. •Approval of expenditure above PCCC authorisation limit is escalated to another Committee or Board meeting. •-Audit and Assurance Committee receives internal audit reports and updates on risk register	Reasonable	•EQC reporting shared with ICB. •NHSE/I remedial actions discussed with ICB •Internal audits of Primary Care Networks and Delegated Commissioning provide reasonable or substantial assurance.	Reasonable	ICB and HCP structures fully implemented and embedded	Approved by Committees meeting in common March 2022 Reviewed by PCB Sept22
PC3	321	04/03/2022	1 2	Primary Care Commissioning Committee	Director of Primary Care Transformation	ENH Head of PC Transformation	**IF** Primary Care is not supported to optimise capacity and address variation, **THEN** patients may not experience improved access to urgent, same day primary care, **RESULTING IN** negative impact on patient experience, patient safety, system resilience and commissioner reputation.	16	12	8	No movement ↔	1. All HWE practices have access to a time limited (to April-23) additional outbound functionality enabled through MS Teams and negotiated nationally. This solution will enable staff to use MS teams to make outbound only calls independently of the existing telephone solutions. This will free up the existing lines for incoming calls. 2. Improvements in practice telephony infrastructure: 55 practices across Hertfordshire and west Essex bids have been approved for implementation in line with the national advance telephony specification. The vast majority of the new system installations having been completed. 3.22/23 Winter Pressure funding of £1.43 per patient & a further £0.602 pp from IIF redeployment 4. Further work in train to reinvigorate patient groups and help promote new healthcare roles and access to services, aligning expectation with offer. 5. GP Transformation plans are currently being agreed for 22/23 work into 23/24. These have a key focus on the implementation of intergrated neighbourhood teams & urgent on the day access. Sept 23 update: All PCNs have an approved Transformation plan in place, place teams supporting on the delivery of these and monitoring outcomes. All PCNs have a Capacity & Access Improvement plan approved as per the requirement of the Primary Care Access Recovery Plan (PCARP), these plans are being supported by place teams. Holding weekly touchpoint internal meetings to monitor the delivery of the PCARP within each place. Same day access proposals are being considered and implemented across each place within the ICB. Access to same day services across system partners is being collated through Transformation leads - this work is currently ongoing. Winter funding - local primary care funding to commission additional activity in primary care at the same level as last year, £1.43 per weighted patient, which will be subject to a PCN plan being appropriate to meet the local and national priorities. This capacity should support surges in practices in PCNs when reaching OPEL 3 or 4	1. Additional demand and constraints of the pandemic. 2. Release of pent-up demand, accumulated during the pandemic when people were less likely to consult their practice or seek specialist care. 3. Need for general practice to take a pivotal role catching up on the backlog of care for patients on its registered list who have ongoing conditions. 4. Tailored practice plans and visits have revealed some themes re barriers to improvements: access to additional IT; premises constraints; workload prioritisation. 5. Actions may require longer term solutions relating to capital investment and workforce development. 6. Expansion of acute in-hours visiting to HV and WE is challenging in the short term due to increased system demand and pressure.	Reports to ICS Executive and Partnership Board Oversight Group discussed emerging issues.	Reasonable	Reports to PCCC	Reasonable	Reports to NHSE/I	Reasonable	Not all proposed measures can be introduced in the short term for all practices.	Approved by Committees meeting in common with the addition of reference to reputational risk. Reviewed by PCB Sept22
PC4	323	13/04/2022	1 2 4	Primary Care Commissioning Committee	Director of Primary Care Transformation	WE Head of PC Transformation	**IF** the pace of organisational development for primary care networks does not increase.. **THEN** there may be insufficient capacity for GP practices, primary care networks and federations to deliver against transformation of care priorities and a limited amount of collaboration between PCNs and other local delivery partners… **RESULTING IN** delays in delivery of transformation objectives to improve quality and accessibility of services.	16	12	8	No movement ↔	1. Provision of additional investment and support to primary care to develop PCNs in planning for the transformation of delivery of care in Hertfordshire and West Essex. 2. PCN DES sign up: national requirements now met for all PCNs and practices. 3. Directorate has a suite of projects designed to increase resilience and sustainability of primary care. 4. Individual work programme risks reviewed at team meetings. 5. HWE ICB Training hub offers/provides training and educational support to PCNs 6. PCN Workforce & PCN Development Plans 7. PCNs provided with Population Health Management support, to develop plan to support specific patient cohorts. 8. Recruitment to ARRS roles. 9. Estates heatmap and rag rating system to support the practices in most need. 10. Girft data dashboard now accessible to monitor and provide early support to practices. 11. Access data dashboard to be launched shortly to give additional valuable data for practices to use in transformation and development. Sept-23 update: ICB has responded to the publication of the Primary Care Access Recovery Plan and is communicating and supporting PCN's with implementation ICB is supporting Practices and PCNs to partcipate in the GP Improvement Programme (GPIP)	1. Further ARRS recruitment to be completed. 2. 2022/23 GP Transformational Support Plans to be agreed and remaining (H2) funding drawn down	Progress reports provided to ICS Primary Care Exec and Partnership Board	Reasonable	Reports to PCB and PCCC	Reasonable	NHSE/I receive PCCC papers	Reasonable		Approved at the PCCCs meeting in common in May 2022. Reviewed by PCB Sept22

Transition Risks

Risk Profile														Assurance Mapping							
ID	Datix ID	Date C	HWEK	Comm	Execut	Revise	CCG Risk Description	Rating	Rating	Rating	Risk M	Controls	Gaps in controls	1st Line Operational functions enforcing required behaviours and working	1st Line	2nd Line Oversight functions undertaking scrutiny and	2nd Line	3rd Line Functions providing independent and objective	3rd Line - Level of	Gaps in assurance	Approval status
PC5	324	04/03/2022	1 2 3 4	Primary Care Commissioning Committee	Director of Primary Care Transformation	AD for Primary Care Contracting	**IF** there are not consistent and rigorous processes for monitoring quality and performance of contracts and investments... **THEN** there is potential for variable outcomes in improvements across the three geographical areas... **RESULTING IN** inequalities in the quality and performance of ICB primary care services and disparities in costs for the same services in different locations.	20	12	8	No movement ↔	1) Individual processes are in place for ICB, for example: -Inclusion of PC data in Quality and Performance reporting to ICB Board - PCCC meeting has independent input from an out of area GP. - PCCC membership has a non-GP majority. - Risk and information sharing meetings with all relevant teams, LMC, Nursing & Quality and CQC. - Support packages in place for all practices with an existing ratings of 'Inadequate' or 'Requires Improvement' - Quality visits to practices and Extended Access sites - Practice Manager meetings 2. Healthwatch action plan 3. Reporting to single ICB Primary Care Board, with non-GP majority membership. Single Primary Care Contracting Panel now in place	1. Review of different approaches in the 3 ICB places **ACTIONS BEING TAKEN**: - Identify current arrangements; compare and identify differences; assess differences in outcomes - Agree which process (or combination of processes) produces the best results - Implement one process across the ICS footprint 2. In process of establishing contractual/performance delivery monitoring processes across the ICS 3. Reviewing approach to joint Quality/Contracts visits. Propose using current WE risk dashboard format as a consistent ICB wide format. 4. Assessment of PCNs needs further consideration - relationship between PCNs & member practices, supervision of PCN staff	Internal quality and performance monitoring processes in each place. Support to practices with 'inadequate' or 'requires improvement' rating. Support to practices with access challenges, e.g. staffing or premises.	Reasonable	Reports to PCB and Quality Group Assurance to PCCC Liaison with CQC and LMC	Reasonable	Liaison with CQC and LMC Internal audit opinions Updates to patient groups e.g. Patient Network Quality (PNQ) Monthly meetings with Healthwatch Presentations at Local Authority Overview and Scrutiny Groups	Reasonable	Extent of reporting of primary care quality and performance to Public Board - for discussion: terms of reference and work plans for ICB committees are being developed by the ICS. There is also discussion of Quality Groups at place at request of the ICS. Some practices reluctant to engage or nor highlighted as potential risks may be inspected by CQC, with further unknown risks emerging.	Approved at the PCCCs meeting in common in May 2022. Reviewed by PCB Sept-22 & agreed to risk score reduction from 16 to 12
PC7	326	04/03/2022	1 2 3	Primary Care Commissioning Committee	Director of Primary Care Transformation	AD for Primary Care Contracting	**IF** Primary Care sustainability is not robust enough... **THEN** we may not be able to ensure continued delivery of primary medical services... **RESULTING IN** a reduction in quality, patient safety and experience.	16	12	4	No movement ↔	1. Routine practice and extended access hub visits. Individual practice visits to support mergers, resource and capacity issues, estates and infrastructure issues 2. Business Continuity Plans - Support for PCNs to develop BCPs and facilitate mutual aid 3. Targeted support for practices who are rated 'inadequate' or 'requires improvement' by the CQC 4. Support offered to all practices for preparation for CQC inspection or other CQC Reviews including 'mock visit' 5. Targeted support where practices have access challenges such as workforce or premises 6. Regular monthly meetings with the CQC 7. Meetings with the LMC 8. Monitor workforce levels through audit 9. Support to practices in the further development of Primary Care Networks as part of the delivery of The Long Term Plan 10. Targeted workforce initiatives through the ICS funding available 11. Supporting practices to access GP Resilience Funding. 12. Primary Care OPEL Framework introduced as part of ECF 13. Potential Practice Closure plans 14. Action plan to identify and investigate opportunities to improve patient access, including promotion of self-care, self-referral and community pharmacy scheme. 15. Additional Roles Reimbursement Scheme for PCNs 16. Additional winter capacity funding for 2022/23 to support the demands faced across the system as a result of the pandemic 17. Support for PCNs to deliver services at scale e.g. Asthma diagnostic hubs Sept-23 update: ICB has responded to the publication of the Primary Care Access Recovery Plan and is communicating and supporting PCN's with implementation ICB is supporting Practices and PCNs to partcipate in the GP Improvement Programme (GPIP)	Solutions to substantive workforce and premises limitations take time to implement. Interim arrangements may need to be actioned.	Available and monitored data sources to gauge practice sustainability: QOF achievement and exception reporting CQC rating GP Patient Survey results Workforce audit information Premises concerns Acute utilisation Quality (complaints & PALS) ICB support requests Risk rating for practice GPAD data	Reasonable	The Primary Care Commissioning Committee reviews the forecast risk resilience tool routinely and also on an ad hoc basis if new information is received. Reports to PCB	Reasonable	CQC inspections and reports	Reasonable		Approved at the PCCCs meeting in common in May 2022. Reviewed by PCB Sept22
PC8	327	04/03/2022	1 2 3	Primary Care Commissioning Committee	Director of Primary Care Transformation	WE Head of PC Transformation	**IF** primary care recovery and prioritisation of workload is not adequately supported... **THEN** meeting of primary care contractual requirements may be affected, particularly relating to routine and preventative work... **RESULTING IN** negative impact on patient access, care and experience, QOF outcomes and wider system pressures.	15	12	6	No movement ↔	1. Additional Winter Capacity Funding support 2. Introduction from Oct-22 of ICB wide ECF scheme to support general practice prioritisation, deliver LTC management etc 3. Dec-22 update - recognising significant winter pressures a review of ECF requirements was undertaken. A risk-based approach has been taken to prioritising key areas, balancing operational pressures (both within primary care and across the wider health system) with the health needs of the population. Aim is to ensure that practices will be able to release clinical capacity to better manage the increase in on the day demands. 4. Further ARRS roles have been developed (Transformation/digital role) 5. Engagement with MDT continues, so backlogs can be cleared 6. Feb-23 update - ICB QOF & IIF mitigation support offer made to all practices & PCNs.	1.Unable to meet high BAU demand 2.Unable to clear back logs for: complex long term conditions; health checks; medication reviews; screening; and spirometry diagnostics. **Actions:** Establish key actions and timescales and monitor progress.	Place based recovery plans for primary care services	Reasonable	Reports to PCB	Reasonable	CQC inspections and reports Internal audit reports External audit conclusions	Reasonable	Ongoing exceptionally high demand in primary care.	Approved at the PCCCs meeting in common in May 2022. Reviewed by PCB Sept22
PC9	328	04/03/2022	2	Primary Care Commissioning Committees meeting in common	Director of Primary Care Transformation	AD for Primary Care Contracting	**IF** the quality of data available to practices and Primary Care Networks is not adequate ... **THEN** this will limit the ability for primary care to meet new responsibilities relating to population health management... **RESULTING IN** failure to achieve forecast outcomes in population health and healthcare and tackle inequalities in outcomes, experience and access.	16	12	4	No movement ↔	1. Procurement of one solution across ICS on data platform i.e. Ardens - Upgraded Ardens Manager 'National Contracts' package procured for practices and PCNs for 2022-23 2. Development of Primary Care Dashboard 3. PCN DES "Tackling Health Inequalities" service implementation 4. Primary Care teams aligned to PCNs/Localities to support development of PCN PHM Plans Sept23 update: Key access data made available to PCNs and practices via Ardens Manager & MS Team folders	1. Currently variance in IT solutions and processes across the CCGs - single BI platform to be implemented 2. Confidence of data recording/reporting 3.Regular /consistent health outcomes and activity data set shared with primary care needs to be established	Co-ordination of consistent BI data reporting across ICS; PHM training to PCNs, Primary Care Managers	Reasonable	Assurance to PCCC	Reasonable	Reporting into ICB	Reasonable	None identified	Approved at the PCCCs meeting in common in May 2022. Reviewed by PCB Sept22
PC10	329	04/03/2022	1 2	Primary Care Commissioning Committee	Director of Primary Care Transformation & Director of Workforce	Head of Primary Care Workforce	**IF** there were no forecasting or forward planning for changes and challenges in general practice workforce... **THEN** we would be unable to foresee changes in workforce and act proactively to address expected shortfalls in any profession... **RESULTING IN** threat to patient care as patients may not have access to a range of skilled professionals in primary care.	9	6	3	No movement ↔	1. Monitoring workforce trends 2. Taking novel approaches to recruitment and retention 3. Providing updates to PCNs including ARRS position 4. Primary Care Teams working with PCNs to submit forward ARRS workforce plans 5. PCN workforce teams connected to current /future issues in practices/PCNs 6. Plan with system partners to avoid destabilising the workforce	1. Increasing numbers of GPs and GPNs taking retirement mean further plans necessary to address retention or recruitment. 2. Difficulties recruiting to some AHP roles due to competition for their skills. 3. PCNs have autonomy for ARRS recruitment plans and have identified finances (shortfall in salary cap and management overheads) and risk (liability for staff given uncertainty about future of PCNs) and perceived value of some non-GP roles as barriers	Quarterly Workforce Data Collection Annual Skill Mix Collection	Substantial	Update reports to PCB and PCCC Progress monitored in ICS Workforce Group	Substantial	Reports to NHSEI	Substantial	None identified	Approved at the PCCCs meeting in common in May 2022. Reviewed by PCB Sept22

Transition Risks

Risk Profile																Assurance Mapping							
ID	Datix ID	Date C	HWEK	Comm	Executi	Revise	CCG Risk Description	Rating	Rating	Rating	Risk M	Controls	Gaps in controls	1st Line Operational functions enforcing required behaviours and working	1st Line	2nd Line Oversight functions undertaking scrutiny and	2nd line	3rd Line Functions providing independent and objective	3rd Level	Gaps in assurance	Approval status
PC11	330	04/01/2022	1 2	Primary Care Commissioning Committee	Director of Primary Care Transformation & Director of Workforce	Head of Primary Care Workforce	**IF** there is a lack of career development opportunities in primary care ... **THEN** primary care may be less attractive as a career choice... **RESULTING IN** doctors, nurses and other allied health professionals leaving primary care and choosing alternative career paths, making primary care less resilient and creating instability in patient access.	12	9	3	No movement ↔	1. Protected Time to Learn Events 2. Qualified Nurses Return to Practice Campaign 3. Qualified Nurses to make PC career choice 4. GP Fellowship Scheme 5. New to Practice Fellowship programme for GPNs and GPs 6. First5 Networking/support forums 7. Wise5 Networking/support forums 8. GPN/HCA networking/support forums 9. Monthly lunch time educational webinars for all Primary Care staff clinical and non clinical 10. Monthly evening educational webinars for clinicians 11. GPN Appraisal support programme 12 .Leadership programmes for GPNs 13. Advanced Care Practitioner networking/support forum 14. GPN Leadership networking/support forum 15. Apprenticeship webinars for clinical and non clinical roles 16. Clinical supervision sessions for GPNs/HCAs 17. HWE ICB Training hub offer all primary care staff career clinic sessions 18. PCN Training Teams	1. Increasing numbers of GPs and GPNs stepping down due to system pressures/ taking early retirement are exacerbating the risk. 2. Difficulties recruiting to primary care roles due to competition for their skills. 3. Underutilisation of ARRS budget	121 line management meetings Workstreams reviewed at Workforce Team meetings Workstreams reviewed at WIG meetings	Reasonable	Reports to PCB and PCCC	Reasonable	Reports to NHSEI Review of workforce position and work programmes at LMC Operational and Liaison Meetings	Reasonable	None identified	Approved at the PCCCs meeting in common in May 2022. Reviewed by PCB Sept22
PC12	331	03/05/2022	1 2	Primary Care Commissioning Committee	Director of Primary Care Transformation	AD for Primary Care Contracting	**IF** the transfer/commencement of the GP Extended Access Service to PCNs is not proactively supported... **THEN** workforce challenges & sub-optimal service delivery is likely ... **RESULTING IN** a.Staff may leave the incumbent provider due to uncertainty caused by the GP Extended Access transfer, resulting in a risk for future provision b.Incumbent providers may lose experienced staff through TUPE which could destabilise their remaining services c. service delivery potentially not meeting patient need, poor utilisation of appointments	16	6	3	Risk rating improved	1. Proactive support to incumbent provider with TUPE. (West Essex specific issue) 2. Agreement of Exit Plan. (West Essex specific issue) 3. Monitor project plan and deliverables and escalate appropriately any deviations - Oct-22 - all staff have transferred to the PCNs now – there are some outstanding issues with a couple of members of staff but the risk is low. 4. Liaison with PCNs to review & agree plans that adequately meet patient need 5. Monthly monitoring of key data - hours provided vs patient utilisation Sept23 update - PROPOSE CLOSURE OF THIS RISK EA fully implemented	1. Two West Essex Extended Access Operational Service Leads have resigned- however HUC are recruiting permanently to these positions and provided reassurance that even if EA is no longer provided by HUC there will be positions for these staff within the IUC contract. 2. More detailed performance monitoring, including use of multi-disciplinary roles, to be agreed 3. Some IT infrastructure issues, especially re the deployment of EMIS hubs, means there will be a transition to full service delivery arrangements 4. Perceived lack of clarity in the PCN specification requirements, especially in terms of % of provision by GPs vs other staff	Exit plan agreed and TUPE support in place (West Essex specific) Monitoring and escalation processes in place.	Reasonable	Reports to PCB and PCCC	Reasonable	LMC engagement	Reasonable	None identified	Approved at the PCCCs meeting in common in May 2022. PCB Nov22 - reviewed and agreed proposed risk score reduction from 16 to 6 Sept23 - PROPOSED CLOSURE OF THIS RISK
PC13	332	03/05/2022	1	Primary Care Commissioning Committee	Director of Primary Care Transformation	Head of Primary Care Workforce	**IF** there were a lack of further training and education opportunities in primary care... **THEN** there would be a failure to keep knowledge relevant and up to date. Capabilities will not be kept up to the same pace as others in the same profession. **RESULTING IN** a. Practice colleagues being unable to maintain and enhance their knowledge and skills needed to deliver primary care to patients. b. Practices would fail their CQC Inspection c. Mental Health issues would increase across the GP population. d. General Practice would have a lack of registered nurses.	6	3	3	No movement ↔	1. Trained Infection Prevention and Control Champions in each practice. 2. The mid-career GP initiative 3. Qualified Practice Nurse Revalidation support 4. Business Fundamentals for GPs 5. Student Placements - nurses and Graduate Managers 6. CPD funding offer for all GPNs/AHPs 7. HWE ICB Career clinics 8. Monthly educational webinars for all health care professionals clinical and non clinical 9. Supporting PCNs to run Protected time to Learn events monthly (reinstated from Nov 2022) 10. Creation of PCN Training Teams	1. Apprenticeships in Primary Care 2. School Engagement and Work Experience Placements 3. Student Placements - other professions	ICS Training Hub ICB Training lead appointed	Reasonable	Reports to PCB and PCCC	Reasonable	National funding in place for Training Hub	Reasonable	Further opportunities to be developed	Approved at the PCCCs meeting in common in May 2022. Reviewed by PCB Sept22
	537	09/11/2022	1 2 3 4	Primary Care Commissioning Committee	Director of Primary Care Transformation	SW Head of PC Transformation	**IF** the Additional Role Reimbursement (ARR) scheme budget is not fully utilised by PCNs **THEN** this available funding for additional primary care roles is lost to individual PCNs & the ICB system **RESULTING IN** a. missed opportunities to provide further additional capacity in general practice b.further pressure on existing workforce c. PCNs may be less able to continue collaborative development d.PCNs less able to meet the requirements of the PCN DES, meaning key prioritise may not be met e. variance in service provision between PCNs	12	12	8	New risk	1. Primary Care Team engagement with PCNs to support with ARRS plans 2. sharing of PCN experiences with ARRS roles via CD/PCN forums 3. Recruitment support offered via Essex Primary Care Careers 4. Further national funding deployed, including PCN Leadership & Management support to improve PCN operational capacity 5. PCN Training Teams being launched to support ARR scheme & wider general practice workforce 6. Further ARRS roles have been developed (Transformation/digital role) Sept23 update: PCN plans for 23/24 being reviewed by Primary Care Team. Balance to be struck between maximising utilisation of ARRS buget vs ensuring that PCNs move towards living within their means (ARRS budget) for 24/25 onwards	1. Further work required on liaison with HPFT re Mental Health PCN roles 2. Reliance on PCN engagement & appetite on recruitment 3. Awaiting further national clarity on ARR scheme funding beyond 23/24	Review by Primary Care SMT	Reasonable	Reports to PCB and PCCC	Reasonable	Reporting to and liaison with NHSE/I Regional Team	Reasonable		Reviewed and approved by PCB Nov-22
	538	09/11/2022	1 2 3 4	Primary Care Commissioning Committee	Director of Primary Care Transformation	SW Head of PC Transformation	**IF** - the closure of Mass COVID-19 Vaccination Centres proceeds as planned, with insufficient contingency **THEN** – there will be increased pressure on PCNs and Community Pharmacy capacity **RESULTING IN** – limited ability to respond to a surge in the C19 vaccination programme, potentially leading to reduction in vaccination availability, lower vaccination rates & consequent wider impact on the healthcare system	9	9	6	New risk	1. Ability for Community Pharmacy & General Practice to scale up operation 2. Working with NHSE to understand likelihood of surge & potential required steps in this scenario NOTE - 24 Feb-23 announcement of Spring Booster campaign, focused initially on care homes & housebound pts; subsequently on over 75s & pts aged 5 and over who are immunosuppressed. Further review of this risk is required, however given this risk specifically focuses on Mass Vaccination Centres then initial thinking is that this campaign is not considered to change the risk rating. A wide Sept23 updates - PROPOSE CLOSURE OF THIS RISK Autumn/Winter (AW) 2023-24 Flu and COVID-19 Seasonal Campaign details published; risk related to previous campaign & no longer relevant. Delivery models across HWE is via Primary Care Networks (PCNs), Community pharmacies and targeted outreach support delivered through Hertfordshire Community Trust.	1. Working with HCT and region to understand the financial impact of maintaining a roving HCT team to support surge 2. PCNs giving notice not to be part of the programme post Autumn program	Contingency plan in the process of being agreed post Autumn program	Reasonable	Reports to PCB and PCCC	Reasonable	National and regional directives being followed	Reasonable	None identified	Reviewed and approved by PCB Nov-22 Sept23 - PROPOSED CLOSURE OF THIS RISK
	617	13/01/2023	1 2	Primary Care Commissioning Committee	Director of Primary Care Transformation	Senior Primary Care Manager - Transformation,Intergration & Delivery	**IF** the growth in the placement of Asylum seekers in local hotels together with growing pressures in general practice continues.. **THEN** agreeing suitable arrangements to register & provide care for this vulnerable cohort of patients becomes increasingly challenged **RESULTING** delays in providing effective care & potential ongoing impact on local 111/A&E services	12	14	6	New risk	1. System wide meetings in place involving various key partners from Home Office, Local Authority/ and District Councils, Voluntary Sector/Hotel Management/Housing Managers to ensure that intelligence is shared and report any issues 2. Collaborative discussion with GP practices, PCNs & LMC to support newly opened hotel facilities 3. Local Enhanced Service spec offered to practices to support with extra workload. ICB has also committed to making this funding available to support spot booking locations, which are not currently supported by NHSE funding. ~~4. One-off payment to Practices where they have registered a Ukrainian National and undertaken a full Health Assessment (payment @£150 per patient) agreed at February PCCC.~~ Sept23 update: 1. Two workshops have taken place to identify a model of working supporting Primary Care - this includes a new specification. To agree full sign-off off Funding Model and Specification by 01/10/23 (stage 1). Stage 2 - to review Dental Opportunity and support. Stage 3 - To review OPTUM opportunity and support (all to be commissioned as in-reach/roving service) 2. All Hotels are now classified as an Intergrated Accomodation Centre (IAC. NHSE Funding Guidance has changed to an allocation model where they will pay the ICB directly (reducing the need for local ICB claims) based on Home Office data. Payment will be made twice per year. 3. Decision made outside of PCCC that Primary Care would stand down market testing. Agreed to review a funding stucture that would support Primary Care practices/PCNS in managing this additional workload and being supported for additional appointment time/need for interpretetors and undertaking of a Initial Health Assesment.	1, New Model of Care initial options discussed at PCCC (February 23) . Further work up required to present the model/spec at the next PCCC (April 23) 2. NHS England is keeping the funding position under review e.g. to establish if spot booked hotels become an enduring feature of Home Office accommodation strategy, whilst recognising the funding pressures on its core and contingency initial accommodation budgets due to unprecedented arrival numbers but acknowledging there is an additional cost pressures on ICBs. A final position on reimbursing from the contingency fund for initial accommodation is expected to be confirmed in January 2023. PCCC February 23 - Updated paper outling costs to date, following the impact of Spot Hotels accross HWE - YTD costs given should the hotels still remain in place, taking into account where NHSE funding offsets some of the ICB costs. 3. New Hotels - since the impact of Spot Hotels (which most have moved to IAC status) there has been no new sites/hotels. We are now aware of a possible 3 new Hotels being stood -up in March 23 (1 in SWH and 2 in WE) potential numbers/occupancy of hotels circa 500 new arrivals. 4. There is potential for increased risk if agreement not reached to extend the current arrangements. New Model of Care would need to be procured for potential new sites & woul not take over the current provision. New Model of Care would be to 'work-up and manage' large cohort numbers, before handing back to Primary Care.	Review by Primary Care SMT	Reasonable	Reports to PCB and PCCC	Reasonable	1. National and regional directives being followed 2. Reporting to and liaison with NHSE/I Regional Team 3 - LMC Liaison and supporting Local Practices/PCN meetings	Reasonable	Primary Care often rarely notified of various new arrivals and/or new sites various (Asylum Seekers, Afghan) - service levels potentially at risk	Reviewed and approved by PCB Jan-23

Transition Risks

Risk Profile														Assurance Mapping							
ID	Datix ID	Date Opened	HWEICS Strategic	Committee	Executive Owner	Revised Risk Lead	CCG Risk Description	Rating (initial)	Rating (current)	Rating (Target)	Risk Movement	Controls	Gaps in controls	1st Line Operational functions enforcing required behaviours and working practices throughout the organisation's day-to-day activities	1st Line - Level of assu	2nd Line Oversight functions undertaking scrutiny and monitoring of the governance framework to ensure that it operate in an efficient and effective	2nd Line - Level of ass	3rd Line Functions providing independent and objective challenge and assurance with regards to the organisation's governance arrangements	3rd Line - Level of assurance	Gaps in assurance	Approval status
Revision of new risk proposed March23		13/09/2023		Primary Care Digital Group	Director of Primary Care Transfor	Head of Primary Care Digital	**IF** the programme is unable to recruit the roles with the relevant skill set knowledge **THEN** there will be a gap in resource and experience needed to develop, deliver and implement the programme **RESULTING IN lack of** progression and delivery of the meaning transformation not delivered and SDF plans not fulfilled	9	9	4	No movement↔	1. Recruitment underway and bandings competetive 2. Using existing resource to porgress where possible 3. If unable to recruit will look to external resource 4. Utilise PCN Digital Leads to assist where possible		Head of Primary Care Digital	Reasonable	Formal Governance via PC Digital Group and PCCC	Reasonable	Digital Boards Reporting to NHSE	Reasonable	Limited options re recruitment	
Revision of new risk proposed March23		13/09/2023		Primary Care Digital Group	Director of Primary Care Transformation	Head of Primary Care Digital	**IF** Digital maturity/ appetite varies across all practices, primary care staff may not able or willing to commit time and resource to allow digital transformation to take place **THEN** There could then be capacity restraint for GP practices, to embed transformation work within the timeframes set out by the programme **RESULTING IN** A poor experience and potential outcome for patients, continued pressure on workforce with primary care and a greater impact on pressure	12	12	6	No movement↔	1. The project will is in place to identify pressure points within primary care to seek solutions 2. Using existing digital resources work on a one on one basis to guide practices and release pressure of change management - including PCN Digital Transformation Leads 3. Establish links with other ICB teams to ascertain support networks and attend necessary meetings 4. Promote the benefits of digital solutions and evidence how they can reduce pressured on primary care 5. GP contract outlines the requirements practices need to deliver digitally 6. Utilise external resources available and amend to suit practice needs 7. Set up working forum/ group to share best practices and challenges and work collaboratively	1. Limited resource to carry out the work 2. Demand and skill sets in place in general practice to manage the change management needed	Head of Primary Care Digital	Reasonable	Formal Governance via PC Digital Group	Reasonable	PC & Digital Boards Reporting to NHSE	Reasonable	May be new pressures currently unknown that push this transformation down priority order	
Revision of new risk proposed March23		13/09/2023		Primary Care Digital Group	Director of Primary Care Tra	Head of Primary Care Digital	**IF** Patients with no access to digital technology cannot remotely connect to primary care **THEN** Their Health and Care could be negatively impacted **RESULTING IN** Poor outcomes and services and widening health Inequalities	16	16	3	No movement ↔	1. Research carried out in the community to ascertain patient needs and challenges contacting GP remotely 2. External commission negates pre conceived ideas internally. 3. Steering group to work through the commission outputs to aide patients who are digitally excluded 4. Socialise the commissioned report with stakeholder to gain commitment and action plans 5. Digital Inclusion part of the wider ICB Digital Strategy	1. Limited resource in the DFPC Team to carry out the work 2. Practices unwilling to support digital in primary care 3. Service design such as websites, making it difficult and frustrating for patients	Head of Primary Care Digital	Reasonable	Formal Governance via PC Digital Group	Reasonable	PC & Digital Boards Reporting to NHSE	Reasonable	Not all proposed measures can be introduced in the short term for all practices.	
New risk - Sep 23		13/09/2023		Primary Care Digital Group	Director of Primary Care Tra	Head of Primary Care Digital	**IF** there are delays to national frameworks/teams/lack of capacity **THEN** we may be unable to move forward certain workstreams (e.g. Cloud Based Telephony) **RESULTING IN** practices not being able to implement improved access	12	12	4	No movement ↔	1.Maintain contacts with national teams to ensure aware of current positions 2.Consider local options as backup 3.Prepare so ready to mobilise as soon as possible 4.Maintain contacts with neighbouring ICBs to maximise benefits of scalability where possible	1. Limited influence over national	Head of Primary Care Digital	Reasonable	Formal Governance via PC Digital Group	Reasonable	PC & Digital Boards Reporting to NHSE	Reasonable	Limited influence over national	
New risk - Sep 23		13/09/2023		Primary Care Digital Group	Director of Primary Care Tra	Head of Primary Care Digital	**IF digital systems in other sectors and elsewhere in primary care do not change/support new ways of working** **THEN** we may be unable to enact required changes **RESULTING IN limited benefits and potentially extra workload on people if they have to enter data into extra places**	12	12	4	No movement ↔	1.Maintain contacts with national teams to ensure aware of current positions 2.Consider local options as backup 3.Prepare so ready to mobilise as soon as possible 4.Maintain contacts with neighbouring ICBs to maximise benefits of scalability where possible	1. Limited influence over national	Head of Primary Care Digital	Reasonable	Formal Governance via PC Digital Group	Reasonable	PC & Digital Boards Reporting to NHSE	Reasonable	Limited influence over national	

Transition Risks

Risk Profile													Assurance Mapping							
ID	Datix ID	Date Opened	Committee	Executive Owner	Risk Lead	CCG Risk Description	Rating (initial)	Rating (current)	Rating (Target)	Risk Movement	Controls	Gaps in controls	1st Line Operational functions enforcing required behaviours and working practices throughout the organisation's day-to-day activities	1st Line - Level of assu	2nd Line Oversight functions undertaking scrutiny and monitoring of the governance framework to ensure that it operate in an efficient and effective	2nd Line - Level of ass	3rd Line Functions providing independent and objective challenge and assurance with regards to the organisation's governance arrangements	3rd Line - Level of assurance	Gaps in assurance	Approval status
New risk - Mar-23		20/02/2023	Primary Care Commissioning Committee	AD Primary Care Contracting	Head of POD Delegation	**POD Delegation - Finance** **IF** 1) the projected large overspend in Community Pharmacy for HWE of £2.5 million is confirmed & the ring-fencing of dental contracts proceeds (historically used to cover the overspend.) and 2) allocation of dental budget in each ICB in line with the population. **THEN** potentially there will be large deficits in budgets for both Community Pharmacy & Dental. **RESULTING IN** inability to deliver transformation projects/increase access for these contractual areas & necessitate redeployment of ICB funding from other priorities	12	12	8	No movement↔	1) Concerns have been highlighted to NHSE as part of the SDC submission 2) the issue is similar across all East of England ICBs and NHSE Region are raising this issue with the National Team 3) given the short time remaining before full delegation from 1st April 23, these are now being escalated by all ICBs. 4) Concerns over the process, lack of information and financial risks have been raised by all ICBs within the East of England Region and escalated to the Director of Primary Care and Public Health		ICB task and finish group are meeting weekly to update on progress and issues Meet regularly with NHSE and other ICBs in the Region to share issues and updates	Reasonable	Reports to PCB and PCCC	Reasonable	ICB Exec	Reasonable		Approved at PCCC Mar-23
New risk - Mar-23		20/02/2023	Primary Care Commissioning Committee	AD Primary Care Contracting	Head of POD Delegation	**POD Delegation - TUPE** **IF** the staff transferred over from NHSE under TUPE arrangements were then subject to future ICBs may be asked to reduce their headcount and running costs **THEN** the ICB may therefore be inheriting redundancy liabilities with the transfer of these staff & have limited resources to absorb the associated workload **RESULTING IN** financial pressure on the ICB &/or reduced ability to undertake the required contractual management functionality	12	12	8	No movement↔	1) Concerns have been highlighted to NHSE as part of the SDC submission 2) the issue is similar across all East of England ICBs and NHSE Region are raising this issue with the National Team 3) given the short time remaining before full delegation from 1st April 23, these are now being escalated by all ICBs. 4) Concerns over the process, lack of information and financial risks have been raised by all ICBs within the East of England Region and escalated to the Director of Primary Care and Public Health Sept23 update - full review of risk will be required, as TUPE issues did not largely emerge. Pharmaceutical and optometry clinical leads transferred from NHSE to HWE to provide support to the fitness process including as case reviewers, providing clinical input in contractual initial and follow up visits with the contracting team. This was not a TUPE transfer for these clinical advisors as they will work ad hoc under a contract for service		ICB task and finish group are meeting weekly to update on progress and issues Meet regularly with NHSE and other ICBs in the Region to share issues and updates	Reasonable	Reports to PCB and PCCC	Reasonable	ICB Exec	Reasonable		Approved at PCCC Mar-23
New risk - Mar-23		20/02/2023	Primary Care Commissioning Committee	AD Primary Care Contracting	Head of POD Delegation	**POD Delegation - Quality** **IF** 1) as planned, there are no quality staff aligned to POD contracts at NHSE, quality review and input to these provider groups is extremely limited and 2) complaints and the national call centre for complaints are part of delegation, with very limited TUPE resourcing **THEN** likely to be unknown issues across providers particularly dentistry where there are high risk procedures, infection prevention and control risks etc; limited ability to manage the required complaints management functionality **RESULTING IN** limited knowledge of & scope to address potential patient safety issues leading to patient harm	15	15	10	No movement ↔	1) Concerns have been highlighted to NHSE as part of the SDC submission 2) the issue is similar across all East of England ICBs and NHSE Region are raising this issue with the National Team 3) given the short time remaining before full delegation from 1st April 23, these are now being escalated by all ICBs. 4) Concerns over the process, lack of information and financial risks have been raised by all ICBs within the East of England Region and escalated to the Director of Primary Care and Public Health		ICB task and finish group are meeting weekly to update on progress and issues Meet regularly with NHSE and other ICBs in the Region to share issues and updates	Reasonable	Reports to PCB and PCCC	Reasonable	ICB Exec	Reasonable		Approved at PCCC Mar-23
	244	08/09/2020	Primary Care Commissioning	AD Primary Care Contracting		If there is a lack of access to dental services then this will impact on a patient's treatment and care resulting in a potential deterioration of health	16	15	6		Further review required to ensure risk reflects changed position with commencement of POD delegation from 1st April 2023 onwards									Approved at PCCC Mar-23

Hertfordshire and West Essex Integrated Care System

NHS Hertfordshire and West Essex Integrated Care Board

Meeting:	*Meeting in public*	☒	*Meeting in private (confidential)*	☐			
	NHS HWE ICB Primary Care Board meeting held in Public				**Meeting Date:**	**28/09/2023**	
Report Title:	**Primary Care Transformation Reports from each Place**				**Agenda Item:**	**08**	
Report Author(s):	Roshina Khan, Head of Primary Care Place SWH Cathy Galione, Head of Primary Care Place ENH Philip Sweeney, Head of Primary Care Place WE< Name, Title, Organisation >						
Report Presented by:	As above.						
Report Signed off by:	Avni Shah Director Primary Care Transformation						
Purpose:	**Approval / Decision**	☐	**Assurance**	☐	**Discussion**	☒	**Information** ☒
Which Strategic Objectives are relevant to this report **[Please list]**	▪ Increase healthy life expectancy, and reduce inequality ▪ Give every child the best start in life ▪ Improve access to health and care services ▪ Increase the numbers of citizens taking steps to improve their wellbeing ▪ Achieve a balanced financial position annually						
Key questions for the ICB Board / Committee:	N/A						
Report History:	N/A						
Executive Summary:	This is the first time since approval of the Primary Care Strategic Delivery Plan for Primary Care Board to start having updates from each respective place. As we are developing our operating model with the development of Health and Care Partnerships, as a Primary care Board the aim is to ensure primary care (GP, Dental, Optometry and Community Pharmacy) is all integrated when looking at transforming care and improving outcomes for our population through the strong development of partners. The aim of this report is to provide the progress being made in delivery against key areas of priorities and how we bring the lived experience and early indication of impact and improvement in outcomes.						

<table>
<tr><td></td><td colspan="4">The paper will evolve as we develop further. For this meeting the board will be provided an update on progress on:
A. Access including progress on National Recovery of Primary Care priority areas, transformation work on same day access in three localities across HWE
B. Prevention and Health inequalities
C. Proactive Management and progress on development of integrated neighbourhood teams.</td></tr>
<tr><td>Recommendations:</td><td colspan="4">The Board is asked to:
Note and discuss the key contents of the report</td></tr>
<tr><td rowspan="4">Potential Conflicts of Interest:</td><td>Indirect</td><td>☐</td><td>Non-Financial Professional</td><td>☐</td></tr>
<tr><td>Financial</td><td>☐</td><td>Non-Financial Personal</td><td>☐</td></tr>
<tr><td colspan="3">None identified</td><td>☒</td></tr>
<tr><td colspan="4"></td></tr>
<tr><td colspan="5">Implications / Impact:</td></tr>
<tr><td>Patient Safety:</td><td colspan="4">n/a</td></tr>
<tr><td>Risk: Link to Risk Register</td><td colspan="4">n/a</td></tr>
<tr><td>Financial Implications:</td><td colspan="4">n/a</td></tr>
<tr><td rowspan="3">Impact Assessments:
(Completed and attached)</td><td colspan="2">Equality Impact Assessment:</td><td colspan="2">N/A</td></tr>
<tr><td colspan="2">Quality Impact Assessment:</td><td colspan="2">N/A</td></tr>
<tr><td colspan="2">Data Protection Impact Assessment:</td><td colspan="2">N/A</td></tr>
</table>

Hertfordshire and West Essex Integrated Care System

Primary Care Update to: **Primary Care Board**

September 2023

Working together
for a healthier future

Primary Care Access Recovery Plan update across ICB;

- All 35 PCNs have an agreed Access Improvement Plan as outlined in the Primary Care Access Recovery Plan.

- Practices are implementing the areas of development and actions in the plan including some practices transitioning to Modern General Practice through understanding of their ever-changing demand and capacity, maximising the use of cloud base telephony where in place, enrolling for the National GP Improvement Programme (19 practices and 4 PCNs), roll out NHS app, online GP registration, development of GP and PCN websites and testing triage models.

- Over 20 sites have been identified for the roll out of cloud base telephony which was approved in July 2023. However, delays in implementation via the national procurement hub which may result in these practices unable to show a change and improvement in telephone access for 2023/24. This has been escalated to the regional team.

- Good progress being made on online access to GP records. Targeted work with 29 practices to enable access by opting into (EMIS) or following self-enablement process (TPP).

- In addition progress being made through partnership working at interface meetings to cut bureaucracy and how we increase self-referrals in number of high volume services such as access to physiotherapy, IAPT, podiatry etc.

- Each system is required to develop an overarching System plan outlining progress against each area of the access recovery plan. ICB assurance meetings on delivery on primary care are now set quarterly with NHS England.

‘Cutting bureaucracy’ update across ICB;

Primary Care Interface liaison – secondary, community & mental health –

- *Secondary care;* Established groups across each place with either a finalised or final draft consensus document shared/signed off with the respective Interface group. The Interface groups will be taking forward some key actions in terms of reducing bureaucracy within the system and reviewing ways of working together.

- *Community services*; interface meetings established to develop working relationships enabling a two way dialogue, agreeing specific actions relating to operational matters, these actions will have measurable outcomes including who is responsible/with timelines. There will be a focus on a couple of key areas to start with and feedback provided on outcomes to respective Clinical Leadership groups.

- *Mental Health services;* This established group meets on a regular basis, action has been taken to increase representation from across places with regular updates to be provided back to the respective Clinical Leadership groups to ensure continued engagement.

Migrant Health update across ICB;

Herts and West Essex ICB currently providing services for approx. 2400 Asylum Seekers.

Timeline of integration and development work to support;

Stage 1 Primary Care Medical Support (anticipated go-live 1st October 2023 – *PCCC to receive updated proposal in October 2023*)

- Includes updated Initial Health Assessment (IHA) – with key areas of screening that must take place within the first 12 weeks
- 2 year specification with review after year 1

Stage 2 Dental

- Scoping work to begin October 23
- Go-live December 23 to January 23

Stage 3 Optometry

- Scoping work to begin January 24
- Go-live March-April 24)

Current Numbers – Hotels

South & West Herts place

- 7 Hotels
- 1 potential new hotel opening in Watford

East & North Herts place

- 8 Hotels
- 1 potential new hotel opening in Broxbourne

West Essex

- 3 Hotels

ECF Progress across the ICB;

East & North Herts place

- The year to date position shows that ENH GP practices have achieved 39% of the total available points. The key areas that practices have made most progress in are: CVD secondary care prevention (95%), and pre-diabetes (71)% and Severe Mental Illness (57%).

- There are pockets of excellent achievement already, ENH practices have achieved higher than Ardens national average on blood pressure checks done on patients with CKD stage 3-5.

- These figures are not unexpected as there are indicators that won't be updated until further into the year, Prescribing for instance.

- One area that requires further focus and progress is Learning Disability Annual Health Checks, with the number of completed checks down on the corresponding period last year. Work is already underway to review data with GP Practices in addition to focussing on the quality of the health checks being undertaken.

ECF Progress across the ICB;

South & West Herts place

- In SWH, 9,804 points have been achieved YTD across the ICBs ECF targets, with 934 remaining.

- The indicators where targets have been reached and nearly reached are Dementia (Frailty & EoL), Safeguarding (General) and Learning Disability (Mental Health). The indicators and assigned targets are set out below for information.

West Essex place

- In West Essex 5,341 points have been achieved YTD, against the 6,215 target

- There is a good even spread of across the ECF domains. Learning Disability (Mental Health) indicators look to be on the lower side but historically they have been completed towards the end of the finicial year and patient have pre planned checks each year. Against previous years data we are on trajectory to meet this target.

Same Day Access across the ICB;

- Continued progress to maximise Community Pharmacy referrals to ensure patients are sent via the correct pathway leaving more appointments for urgent on the day access.

- Expansion of Urgent care teams in practice to improve UOTD access for F2F assessments Frequent flyers" dealt with by the practice High Intensity User team

- Same day access hub proposals for Stevenage North and South PCNs (in ENH place) with the HCP Virtual Transformation group linked with East & North Herts NHS Trust in terms of their UEC workstream and how the Stevenage same day access model can be linked for impact and outcome measures.

South & West Herts place update

Integrated Neighbourhood Teams

- Sixteen Primary Care Networks making up four Integrated Neighbourhood Teams.
- Using existing locality geography structures that have decision making representation from each of the member organisations.
- Adopting a Population Health Management (PHM) approach, using segmentation model and risk stratification
- **Hertsmere** have chosen Complex Mental Health - SMI/LD as their INT project
- **Dacorum -** Dacorum Locality Provider Delivery Group will be meeting on 19th September to discuss two projects focusing on patients with severe and complex frailty working in partnership with CLCH, WHTHT and St Francis Hospice. Other areas identified are Heart Failure and High Intensity users working with WHTHT.
- **Watford –** recent workshop ‘One Watford’ via Watford District Council reviewing key partnerships for an successful INT group.
- **St Albans & Harpenden** to meet on 21st September to identify project

East & North Herts place update

Integrated Neighbourhood Teams

- This key area of work is being driven at place collaboratively with our Health and Care Partnership; it is recognised that different parts of East and North Hertfordshire currently have varying levels of development and maturity of their INTs.

- The HCP's Care Closer to Home Steering Group agreed to focus on playing more of an 'enabling' role; supporting local delivery by co-ordinating resources, tackling strategic issues, and overcoming barriers.

- The programme is taking an incremental approach to the development of INTs, with small improvements building to longer-term change. The programme will take a light touch approach to governance arrangements, ensuring that INT staff feel empowered to make local decisions for the implementation of their models.

- Welwyn Garden City and Hoddesdon and Broxbourne Primary Care Network's (PCN's) have agreed to be the vanguards using Population Health Management data to implement the INT model. The next step is to have a robust INT plan in place from October 2023 for each of these PCN's.

West Essex place update

Integrated neighbourhood teams

- INT Leadership teams established (on PCN footprint), running effectively and good engagement across all partners
- Frontline staff aligned to INTs and permission from leaders to their teams to break down the barriers to integration and be innovative.
- INTs key element of primary care strategy and WE place out of hospital strategy, linking with intermediate care, virtual hospital, care coordination centre programmes
- Proactive care model commenced using a PHM approach for risk stratification and identification of cohort for proactive care cohort. ARRS care coordinator role being used.
- Effective matrix working across ICB primary care, transformation, PHM teams
- Care home hub pilot in Loughton, Buckhurst Hill & Chigwell PCN, using GP fellow and ARRS staff
- Ongoing review and development approach

Place Based Transformation projects;

West Essex place – Integrated Urgent Assessment and Treatment Centre has been commissioned and will go live with effect from 1st November 2023 From November, Integrated Urgent Assessment and Treatment centre live in Harlow, provided by system partners working together as a provider collaborative. New way of working in an integrated way, delivering same day access either on site or linking with MIUs, primary care or wider community services.

2 PCNs likely to offer additional winter capacity on hub/shared PCN basis, building on approaches in 22/23

South & West Herts place – Hertsmere Minor Illness Bookable Hub business case developed and going to HCP board for approval.

East & North Herts place – *Welwyn Garden City PCN; 'Reach & Teach' pilot working with East & North Hertfordshire NHS Trust*;

- Bring primary and secondary care together – Consultants upskilling GPs
- Engage patients, avoid admissions through proactive management / outreach

Two "mini-pilots" already happened;

- Gastro specialist – referrals seen in general practice.
- Diabetes specialist – 6 disengaged type 1 DM seen in general practice

- Next steps for: MDT covering renal and cardiology – joined up patient care and reduce contacts required. Also linking to their INT development work and identified patient co-hort.

Hertfordshire and West Essex Integrated Care System

NHS Hertfordshire and West Essex Integrated Care Board

Meeting:	*Meeting in public*	☒	*Meeting in private (confidential)*	☐
	NHS HWE ICB Primary Care Board meeting held in Public		**Meeting Date:**	**28/09/2023**
Report Title:	**Enhanced Commissioning Framework 2022/23 Review**		**Agenda Item:**	**09**
Report Author(s):	Dr Sam Williamson, Associate Medical Director, HWE ICB			
Report Presented by:	Dr Sam Williamson, Associate Medical Director, HWE ICB			
Report Signed off by:	Avni Shah, Director of Primary Care			
Purpose:	**Approval / Decision** ☐	**Assurance** ☐	**Discussion** ☐	**Information** ☒
Which Strategic Objectives are relevant to this report **[Please list]**	▪ Increase healthy life expectancy, and reduce inequality ▪ Improve access to health and care services ▪ Increase the numbers of citizens taking steps to improve their wellbeing ▪ Achieve a balanced financial position			
Key questions for the ICB Board / Committee:	▪ The Board are asked to note the findings from the review of the ECF 2022/23.			
Report History:	▪ N/A			
Executive Summary:	The Enhanced Commissioning Framework (ECF) was implemented in October 2022 across HWE ICS and provides practices with additional funding for the delivery of care that meets local needs and priorities. Due to pressures on primary care in December 2022, the ECF was revised to streamline care and provide practices with security. The review reduced the number of indicators requiring reporting and lowered the thresholds for achieving full payment. This review assesses performance of practices across the indicators within the ECF. The review highlights the significant efforts undertaken in primary care to deliver core elements of patient care for people with a range of conditions. It also highlights how proactive care has seen progress towards full restoration to pre-pandemic levels. However, it highlights significant variation in care delivery across all indicators. The care delivered as part of the ECF has supported people to receive proactive care both in general practice as well as through specialist services as a result of onward referral.			

	The ECF supports the national and ICB priorities of improving proactive management of long term conditions and frailty as well as improving the identification of long term conditions. The Board are asked to note that insights from the ECF 22/23 are limited due to the scheme only being implemented for 6 months of the year. In addition, comparison to other ICSs is not yet possible due to lag time in national benchmarking data. Furthermore, the impacts of delivering care (e.g. reducing episodes of unplanned care) will be observed over a longer time period and will be confounded by service developments across other parts of the system (e.g. hospital at home). Despite these limitations, early positive findings include a reduction in the number of people who are classified as having high risk type 2 diabetes, improved identification of people who are in their last year of life and higher levels of spirometry episodes that will support better and earlier diagnosis of long term respiratory conditions. Areas that were challenging to deliver included assessing people at risk of frailty, completing falls assessments in people with frailty and elements of physical health checks for people with serious mental illnesses. Performance in 23/24 can be increased through 'bedding in' of processes in practices and ongoing adoption of the ECF, as well as further development and training support to primary care staff in the delivery of these aspects of care. The findings from the review of ECF 22/23 as well as interim findings from ECF 23/24 and wider information will support the ongoing development of the ECF. Key elements for further development include: • Reducing unwarranted variation in care and outcomes through differences in performance. • Ongoing improvements to the standardised coding of information to enable information sharing across the system.
Recommendations:	▪ Board members can support reductions in variation through the ongoing work undertaken as part of the ECF and wider initiatives (e.g. training and development support). ▪ Learning should be taken from practices achieving high levels of performance to understand the processes adopted and this information shared across practices within the ICS. Findings from the ▪ ECF review 22/23 will be incorporated, along with wider insights on population health into the future plans for ECF 24/25.

Potential Conflicts of Interest:	***Indirect***	☐	***Non-Financial Professional***	☐
	Financial	☒	***Non-Financial Personal***	☐
	None identified			☐

	Members of the Primary Care Board receive financial benefit from the ECF scheme.	
Implications / Impact:		
Patient Safety:	*No risks identified*	
Risk: *Link to Risk Register*	*No risks identified*	
Financial Implications:	*[State funding costs and potential savings]*	
Impact Assessments: *(Completed and attached)*	***Equality Impact Assessment:***	N/A
	Quality Impact Assessment:	N/A
	Data Protection Impact Assessment:	N/A

Hertfordshire and West Essex Integrated Care System

NHS
Hertfordshire and West Essex
Integrated Care Board

2022/23 ECF performance data
Ardens Manager

August 2023

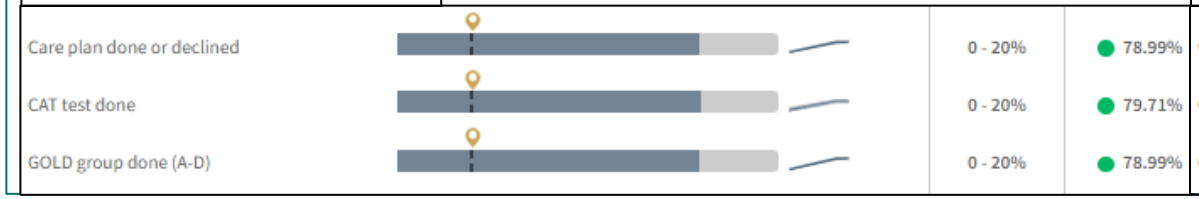
Working together
for a healthier future

COPD

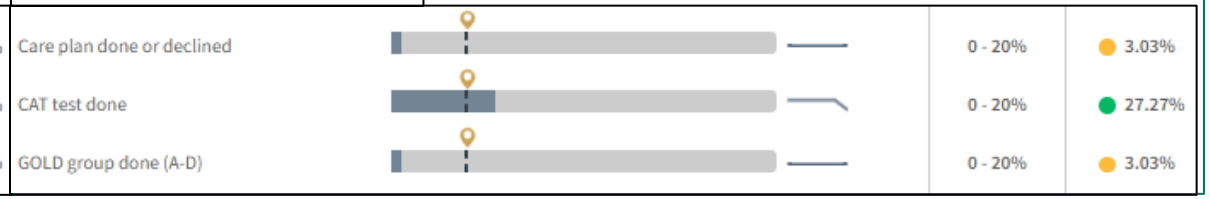
ICB Overall Performance

Overall, practices achieved 92% of the available points for COPD, reflecting the reduced clinical indicators and lower thresholds.
CAT scoring (60.7%) was the highest indicator and GOLD group scoring was the lowest (35.8%). However, the greatest variation is apparent at the practice level, where some practices achieved very strong performance (over 75% across all three indicators) compared with practices that delivered/coded no activity or partial activity across some indicators.
It is recommended that regular reviews of ECF data by the ICB are used to support practice discussions and identify areas of poorer performance.

High performing practice



Low performing practice



Hertfordshire and West Essex Integrated Care System

COPD

ICB Clinical Metrics

COPD

Benchmark Hertfordshire and West Essex ICS organisations			THRESHOLDS	ACHIEVED %	POINTS	
Clinical Activity					1,080.68 / 1,170	
Review	Care plan done or declined		0 - 20%	50.48%	618.97 / 650	12,720 / 25,199
	CAT test done		0 - 20%	60.93%	250.5 / 260	15,355 / 25,199
	GOLD group done (A-D)		0 - 20%	36.04%	211.21 / 260	9,082 / 25,199

COPD

PCN Achievement (Hertfordshire)

East & North Herts	Care plan done or declined		CAT test done		GOLD group done (A-D)	
	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold
Broxbourne Alliance	55%	20%	62%	20%	53%	20%
Hatfield PCN	50%	20%	63%	20%	46%	20%
Hertford and Rurals PCN	27%	20%	36%	20%	22%	20%
Hitchin & Whitwell PCN	74%	20%	78%	20%	60%	20%
Hoddesdon and Broxbourne PCN	74%	20%	74%	20%	52%	20%
Icknield PCN	54%	20%	65%	20%	32%	20%
Lea Valley Health PCN	70%	20%	74%	20%	39%	20%
Stevenage North PCN	58%	20%	47%	20%	39%	20%
Stevenage South PCN	57%	20%	66%	20%	33%	20%
Stort Valley and Villages PCN	56%	20%	63%	20%	44%	20%
Ware and Rurals PCN	69%	20%	61%	20%	26%	20%
Welwyn Garden City PCN	46%	20%	67%	20%	61%	20%

South West Herts	Care plan done or declined		CAT test done		GOLD group done (A-D)	
	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold
Abbey Health PCN	50%	20%	74%	20%	54%	20%
Alban Healthcare PCN	29%	20%	25%	20%	9%	20%
Alliance PCN	21%	20%	56%	20%	1%	20%
Alpha PCN	35%	20%	59%	20%	28%	20%
Attenborough & Tudor PCN	32%	20%	2%	20%	1%	20%
Central Watford PCN	50%	20%	45%	20%	39%	20%
Dacorum Beta PCN	35%	20%	67%	20%	29%	20%
Delta PCN	41%	20%	62%	20%	29%	20%
HaLo PCN	8%	20%	78%	20%	35%	20%
Harpenden PCN	39%	20%	37%	20%	31%	20%
Herts Five PCN	52%	20%	72%	20%	43%	20%
Manor View PCN	77%	20%	73%	20%	2%	20%
North Watford PCN	44%	20%	64%	20%	0%	20%
Potters Bar PCN	41%	20%	62%	20%	36%	20%
Rickmansworth & Chor	45%	20%	59%	20%	40%	20%
The Grand Union PCN	42%	20%	55%	20%	26%	20%

COPD

PCN Achievement (West Essex)

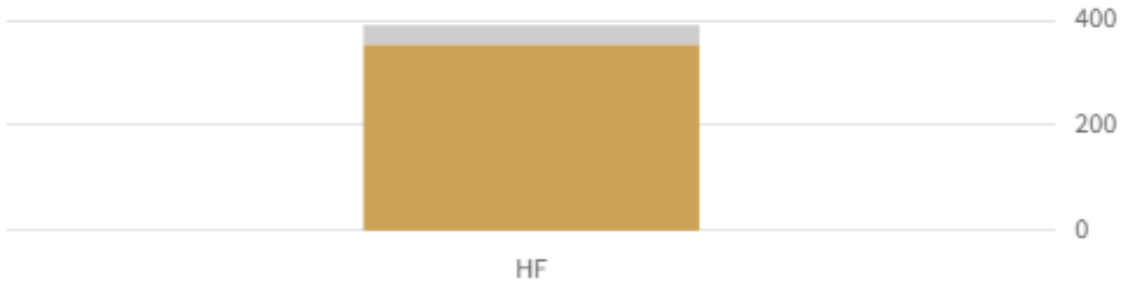
West Essex	Care plan done or declined		CAT test done		GOLD group done (A-D)	
	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold
Epping Ongar Abridge Waltham Abbey PCN	45%	20%	52%	20%	32%	20%
Harlow North PCN	55%	20%	66%	20%	43%	20%
Harlow South PCN	53%	20%	67%	20%	32%	20%
Loughton Buckhurst Hill & Chigwell PCN	65%	20%	69%	20%	50%	20%
North Uttlesford PCN	55%	20%	63%	20%	47%	20%
South Uttlesford PCN	55%	20%	66%	20%	44%	20%

CVD

ICB Overall Performance

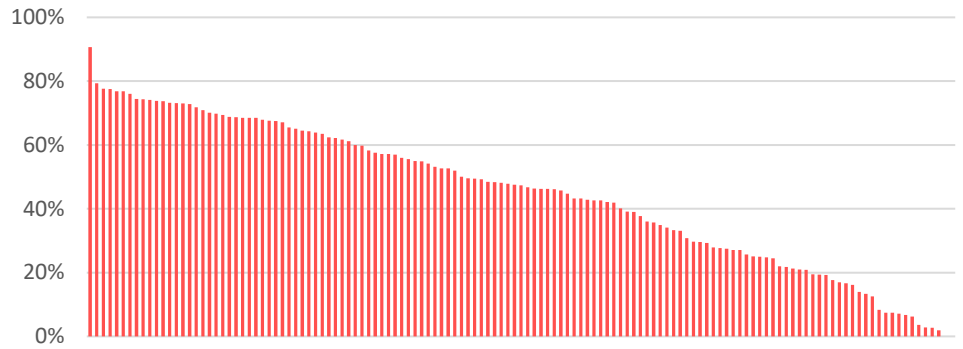
CVD : Hertfordshire and West Essex I...

352.82/390 points achieved
(233/2,078 INDICATOR TARGETS REACHED)



Overall, practices achieved 90% of the available points for CVD, reflecting the reduced clinical indicators and lower thresholds. There were significant reductions in the number of indicators with associated points upon review in December ’22.
45% of people with heart failure received an up to date NYHA classification, supporting more targeted care. However, significant variation exists across practices (0-91%).

Proportion of people with Heart Failure who had an NYHA classification recorded during 22/23



Hertfordshire and West Essex Integrated Care System

CVD

ICB Clinical Metrics

HEART FAILURE

Benchmark Hertfordshire and West Essex ICS	organisations	THRESHOLDS	ACHIEVED %	POINTS	
Clinical Activity				352.82 / 390	
NYHA classification done		0 - 20%	45.45%	352.82 / 390	6,538 / 14,386

Hertfordshire and West Essex Integrated Care System

CVD PCN Achievement (Hertfordshire)

East & North Herts	NYHA classification done	
	Achievement	Threshold
Broxbourne Alliance	63%	20%
Hatfield PCN	46%	20%
Hertford and Rurals PCN	29%	20%
Hitchin & Whitwell PCN	66%	20%
Hoddesdon and Broxbourne PCN	57%	20%
Icknield PCN	29%	20%
Lea Valley Health PCN	51%	20%
Stevenage North PCN	23%	20%
Stevenage South PCN	45%	20%
Stort Valley and Villages PCN	44%	20%
Ware and Rurals PCN	67%	20%
Welwyn Garden City PCN	60%	20%

South West Herts	NYHA classification done	
	Achievement	Threshold
Abbey Health PCN	36%	20%
Alban Healthcare PCN	41%	20%
Alliance PCN	5%	20%
Alpha PCN	50%	20%
Attenborough & Tudor PCN	25%	20%
Central Watford PCN	35%	20%
Dacorum Beta PCN	44%	20%
Delta PCN	43%	20%
HaLo PCN	55%	20%
Harpenden PCN	46%	20%
Herts Five PCN	47%	20%
Manor View PCN	64%	20%
North Watford PCN	38%	20%
Potters Bar PCN	35%	20%
Rickmansworth & Chor	47%	20%
The Grand Union PCN	44%	20%

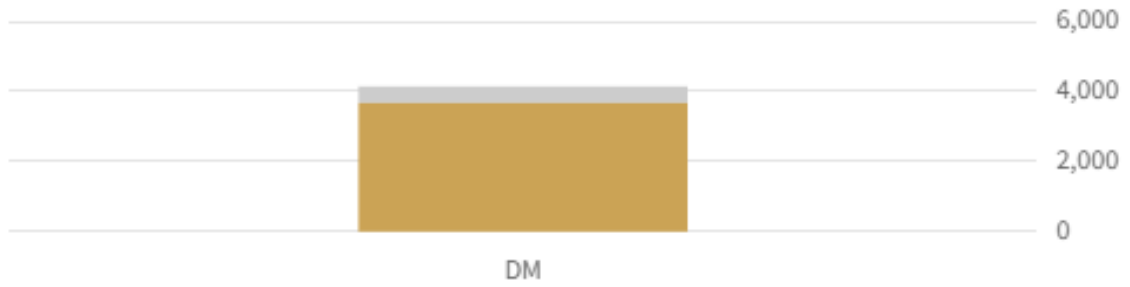
West Essex	NYHA classification done	
	Achievement	Threshold
Epping Ongar Abridge Waltham Abbey PCN	51%	20%
Harlow North PCN	42%	20%
Harlow South PCN	39%	20%
Loughton Buckhurst Hill & Chigwell PCN	50%	20%
North Uttlesford PCN	44%	20%
South Uttlesford PCN	48%	20%

Diabetes

ICB Overall Performance

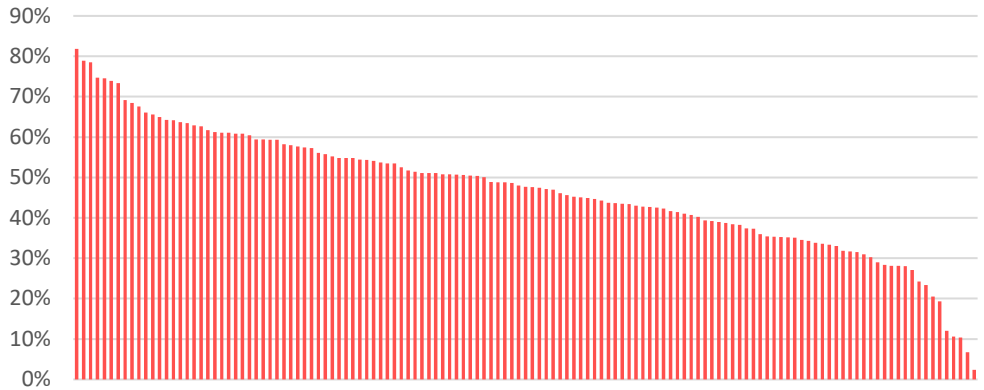
Diabetes : Hertfordshire and West Essex I...

3,669.92/4,142 points achieved
(198/3,353 INDICATOR TARGETS REACHED)



Practices achieved 89% of ECF points in the diabetes section. A higher proportion of points were attained for delivering care processes in high risk diabetics (89%) than completing structured medication reviews for people at risk of hypoglycaemia (73%).
The number of indicators in diabetes were reduced at the December review to prioritise care for people with high risk diabetes. Upper thresholds were maintained at 40% for the remaining indicators.
The majority of practices delivered care to at least 40% of the cohort, with some practices far out performing the target, achieving 70%+. However, there remains significant variation at practice level which will impact on clinical outcomes as well as unplanned care.
A key finding from the analysis is that the number of people that are now classified as being ‘high risk’ has reduced by nearly 3,500, reflecting proactive management and improved glycaemic control.

Proportion of people classified as having 'high risk type 2 diabetes' who had all 8 care processes completed during 22/23



Hertfordshire and West Essex Integrated Care System

Diabetes

ICB Clinical Metrics

DIABETES

Benchmark Hertfordshire and West Essex ICS organisations			THRESHOLDS	ACHIEVED %	POINTS	
Clinical Activity					3,669.92 / 4,142	
Prescribing	SMR or DM drug review if >75y + on sulphonylurea + Hb1Ac <48		0 - 40%	53.45%	177.08 / 242	178 / 333
Review	All 8 care processes done + UCLP high risk		0 - 40%	46.29%	3,492.84 / 3,900	10,079 / 21,774

Diabetes PCN Achievement (Hertfordshire)

East & North Herts	SMR or DM drug review if >75y + on sulphonylurea + Hb1Ac <48		All 8 care processes done + UCLP high risk	
	Achievement	Threshold	Achievement	Threshold
Broxbourne Alliance	65%	40%	48%	40%
Hatfield PCN	40%	40%	49%	40%
Hertford and Rurals PCN	29%	40%	19%	40%
Hitchin & Whitwell PCN	71%	40%	44%	40%
Hoddesdon and Broxbourne PCN	40%	40%	57%	40%
Icknield PCN	15%	40%	43%	40%
Lea Valley Health PCN	36%	40%	53%	40%
Stevenage North PCN	63%	40%	41%	40%
Stevenage South PCN	56%	40%	48%	40%
Stort Valley and Villages PCN	70%	40%	50%	40%
Ware and Rurals PCN	100%	40%	60%	40%
Welwyn Garden City PCN	100%	40%	53%	40%

South West Herts	SMR or DM drug review if >75y + on sulphonylurea + Hb1Ac <48		All 8 care processes done + UCLP high risk	
	Achievement	Threshold	Achievement	Threshold
Abbey Health PCN	17%	40%	51%	40%
Alban Healthcare PCN	43%	40%	55%	40%
Alliance PCN	31%	40%	32%	40%
Alpha PCN	92%	40%	53%	40%
Attenborough & Tudor PCN	100%	40%	43%	40%
Central Watford PCN	75%	40%	40%	40%
Dacorum Beta PCN	44%	40%	48%	40%
Delta PCN	20%	40%	52%	40%
HaLo PCN	88%	40%	61%	40%
Harpenden PCN	100%	40%	60%	40%
Herts Five PCN	84%	40%	56%	40%
Manor View PCN	67%	40%	56%	40%
North Watford PCN	67%	40%	44%	40%
Potters Bar PCN	73%	40%	43%	40%
Rickmansworth & Chor	60%	40%	48%	40%
The Grand Union PCN	69%	40%	48%	40%

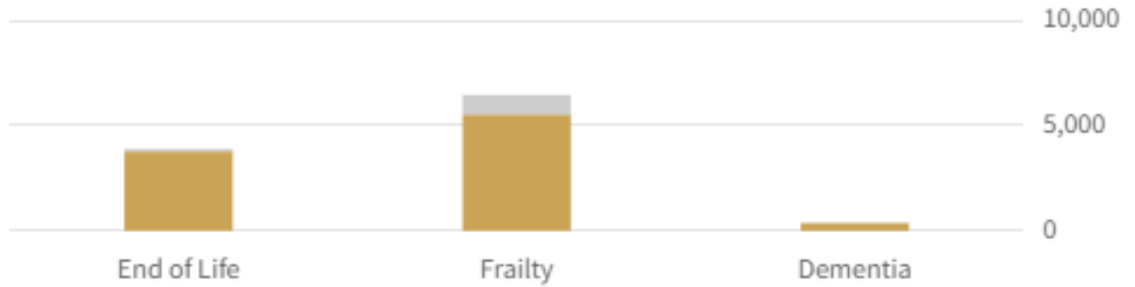
West Essex	SMR or DM drug review if >75y + on sulphonylurea + Hb1Ac <48		All 8 care processes done + UCLP high risk	
	Achievement	Threshold	Achievement	Threshold
Epping Ongar Abridge Waltham Abbey PCN	44%	40%	34%	40%
Harlow North PCN	17%	40%	35%	40%
Harlow South PCN	86%	40%	49%	40%
Loughton Buckhurst Hill & Chigwell PCN	17%	40%	34%	40%
North Uttlesford PCN	90%	40%	47%	40%
South Uttlesford PCN	54%	40%	48%	40%

Frailty & End of Life

ICB Overall Performance

Frailty & EoL : Hertfordshire and West Essex I...

9,621.49/10,734 points achieved
(1,599/2,977 INDICATOR TARGETS REACHED)



The frailty and end of life sections contained the most ECF points, with 10,734 total available points in these two areas.
In general practices delivered care and met the thresholds across the indicators. However, the thresholds for end of life were reduced to 20% and frailty to 30% at the December review and there were indicators that were removed from reporting.
As with other areas, variation was observed across practices, with many surgeries far exceeding the thresholds, in particular for end of life care.
The areas with the greatest gaps in delivery were assessing falls risk, recording carer status and documenting the current frailty status.
There were also further opportunities to improve the identification of people living with frailty, with only 19.6% of people who are at risk of being frail being assessed.
A key finding from the data is that practices in SWH had lower performance across end of life metrics. This is likely to reflect the fact that community palliative care services record much of this information. However, critically, this information on advance care planning and treatment escalation plans is not being recorded into the clinical record in primary care.

Frailty & End of Life

ICB Clinical Metrics

FRAILTY

Benchmark Hertfordshire and West Essex ICS organisations			THRESHOLDS	ACHIEVED %	POINTS	
Clinical Activity					5,513.45 / 6,448	
Prescribing	Moderate frailty + SMR or polypharmacy medication review		0 - 40%	95.58%	2,397.4 / 2,451	16,051 / 16,794
Review	Mod/Sev + carer status recorded		0 - 30%	32.59%	692.72 / 903	12,996 / 39,875
	Mod/Sev + falls FRAT score done		0 - 30%	26.31%	682.86 / 1,032	10,490 / 39,875
	Mod/Sev + frailty assessment done		0 - 30%	94.98%	888.13 / 903	37,873 / 39,875
	Mod/Sev + frailty score recorded - Rockwood		0 - 30%	41.43%	735.06 / 903	16,521 / 39,875
Screening	Frailty status or Rockwood score done if >65y + conditions		0 - 40%	19.67%	117.29 / 256	15,214 / 77,334

Frailty PCN Achievement (Hertfordshire)

East & North Herts	Moderate frailty + SMR or polypharmacy medication review		Mod/Sev + carer status recorded		Mod/Sev + falls FRAT score done		Mod/Sev + frailty assessment done		Mod/Sev + frailty score recorded - Rockwood		Frailty status or Rockwood score done if >65y + conditions	
	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold
Broxbourne Alliance	84%	40%	57%	30%	54%	30%	85%	30%	70%	30%	36%	40%
Hatfield PCN	100%	40%	35%	30%	27%	30%	100%	30%	64%	30%	46%	40%
Hertford and Rurals PCN	40%	40%	27%	30%	13%	30%	48%	30%	30%	30%	10%	40%
Hitchin & Whitwell PCN	100%	40%	37%	30%	32%	30%	100%	30%	49%	30%	28%	40%
Hoddesdon and Broxbourne PCN	100%	40%	40%	30%	39%	30%	100%	30%	73%	30%	35%	40%
Icknield PCN	100%	40%	31%	30%	23%	30%	100%	30%	42%	30%	12%	40%
Lea Valley Health PCN	100%	40%	67%	30%	51%	30%	99%	30%	66%	30%	23%	40%
Stevenage North PCN	100%	40%	36%	30%	34%	30%	98%	30%	87%	30%	41%	40%
Stevenage South PCN	100%	40%	36%	30%	32%	30%	80%	30%	57%	30%	14%	40%
Stort Valley and Villages PCN	100%	40%	31%	30%	33%	30%	75%	30%	47%	30%	28%	40%
Ware and Rurals PCN	100%	40%	57%	30%	38%	30%	99%	30%	63%	30%	14%	40%
Welwyn Garden City PCN	100%	40%	45%	30%	37%	30%	100%	30%	49%	30%	10%	40%

Frailty

PCN Achievement (Hertfordshire)

South West Herts	Moderate frailty + SMR or polypharmacy medication review		Mod/Sev + carer status recorded		Mod/Sev + falls FRAT score done		Mod/Sev + frailty assessment done		Mod/Sev + frailty score recorded - Rockwood		Frailty status or Rockwood score done if >65y + conditions	
	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold
Abbey Health PCN	100%	40%	48%	30%	36%	30%	99%	30%	48%	30%	13%	40%
Alban Healthcare PCN	100%	40%	67%	30%	13%	30%	100%	30%	45%	30%	39%	40%
Alliance PCN	100%	40%	6%	30%	1%	30%	100%	30%	3%	30%	6%	40%
Alpha PCN	100%	40%	23%	30%	19%	30%	100%	30%	32%	30%	40%	40%
Attenborough & Tudor PCN	100%	40%	2%	30%	0%	30%	100%	30%	2%	30%	6%	40%
Central Watford PCN	100%	40%	27%	30%	49%	30%	100%	30%	47%	30%	37%	40%
Dacorum Beta PCN	100%	40%	30%	30%	34%	30%	100%	30%	50%	30%	24%	40%
Delta PCN	100%	40%	13%	30%	15%	30%	100%	30%	22%	30%	20%	40%
HaLo PCN	100%	40%	48%	30%	25%	30%	100%	30%	53%	30%	14%	40%
Harpenden PCN	100%	40%	56%	30%	43%	30%	100%	30%	66%	30%	40%	40%
Herts Five PCN	100%	40%	44%	30%	38%	30%	100%	30%	40%	30%	48%	40%
Manor View PCN	100%	40%	37%	30%	31%	30%	82%	30%	29%	30%	29%	40%
North Watford PCN	100%	40%	9%	30%	13%	30%	100%	30%	35%	30%	35%	40%
Potters Bar PCN	100%	40%	26%	30%	19%	30%	100%	30%	23%	30%	5%	40%
Rickmansworth & Chor	100%	40%	37%	30%	36%	30%	99%	30%	41%	30%	49%	40%
The Grand Union PCN	100%	40%	46%	30%	44%	30%	99%	30%	57%	30%	27%	40%

Frailty PCN Achievement (West Essex)

West Essex	Moderate frailty + SMR or polypharmacy medication review		Mod/Sev + carer status recorded		Mod/Sev + falls FRAT score done		Mod/Sev + frailty assessment done		Mod/Sev + frailty score recorded - Rockwood		Frailty status or Rockwood score done if >65y + conditions	
	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold
Epping Ongar Abridge Waltham Abbey PCN	75%	40%	24%	30%	12%	30%	85%	30%	27%	30%	2%	40%
Harlow North PCN	100%	40%	31%	30%	12%	30%	96%	30%	38%	30%	14%	40%
Harlow South PCN	100%	40%	23%	30%	17%	30%	100%	30%	22%	30%	2%	40%
Loughton Buckhurst Hill & Chigwell PCN	100%	40%	31%	30%	10%	30%	100%	30%	40%	30%	3%	40%
North Uttlesford PCN	100%	40%	23%	30%	18%	30%	90%	30%	20%	30%	4%	40%
South Uttlesford PCN	100%	40%	30%	30%	13%	30%	100%	30%	28%	30%	6%	40%

End of Life

ICB Clinical Metrics

END OF LIFE

Benchmark Hertfordshire and West Essex ICS organisations			THRESHOLDS	ACHIEVED %	POINTS	
Clinical Activity					3,621.04 / 3,766	
Review	Anticipatory medicines if GSF red/yellow		0 - 20%	61.31%	468.33 / 516	263 / 429
	Preferred place of care recorded		0 - 20%	51.72%	236.29 / 260	3,704 / 7,162
	Preferred place of death recorded		0 - 20%	52.02%	230.33 / 260	3,726 / 7,162
	Resus status recorded		0 - 20%	55.67%	256.14 / 260	3,987 / 7,162
Screening	GSF status if severe COPD, HF, CKD or frailty		0 - 20%	94.27%	2,429.96 / 2,470	13,438 / 14,255

End of Life PCN Achievement (Hertfordshire)

East & North Herts	Anticipatory medicines if GSF red/yellow		Preferred place of care recorded		Preferred place of death recorded		Resus status recorded		GSF status if severe COPD, HF, CKD or frailty	
	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold
Broxbourne Alliance	71%	20%	70%	20%	68%	20%	60%	20%	81%	20%
Hatfield PCN	69%	20%	73%	20%	79%	20%	70%	20%	100%	20%
Hertford and Rurals PCN	38%	20%	33%	20%	34%	20%	37%	20%	90%	20%
Hitchin & Whitwell PCN	48%	20%	63%	20%	58%	20%	57%	20%	100%	20%
Hoddesdon and Broxbourne PCN	100%	20%	61%	20%	77%	20%	54%	20%	100%	20%
Icknield PCN	68%	20%	67%	20%	70%	20%	64%	20%	100%	20%
Lea Valley Health PCN	67%	20%	71%	20%	69%	20%	47%	20%	99%	20%
Stevenage North PCN	63%	20%	69%	20%	92%	20%	59%	20%	98%	20%
Stevenage South PCN	79%	20%	71%	20%	77%	20%	70%	20%	99%	20%
Stort Valley and Villages PCN	53%	20%	59%	20%	59%	20%	48%	20%	43%	20%
Ware and Rurals PCN	45%	20%	73%	20%	66%	20%	64%	20%	97%	20%
Welwyn Garden City PCN	70%	20%	71%	20%	60%	20%	45%	20%	100%	20%

End of Life

PCN Achievement (Hertfordshire)

South West Herts	Anticipatory medicines if GSF red/yellow		Preferred place of care recorded		Preferred place of death recorded		Resus status recorded		GSF status if severe COPD, HF, CKD or frailty	
	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold
Abbey Health PCN	100%	20%	13%	20%	13%	20%	44%	20%	100%	20%
Alban Healthcare PCN	100%	20%	20%	20%	18%	20%	51%	20%	100%	20%
Alliance PCN	100%	20%	15%	20%	10%	20%	17%	20%	100%	20%
Alpha PCN	20%	20%	33%	20%	28%	20%	48%	20%	100%	20%
Attenborough & Tudor PCN	75%	20%	54%	20%	46%	20%	68%	20%	100%	20%
Central Watford PCN	0%	20%	54%	20%	53%	20%	61%	20%	93%	20%
Dacorum Beta PCN	77%	20%	26%	20%	43%	20%	35%	20%	100%	20%
Delta PCN	100%	20%	10%	20%	12%	20%	34%	20%	98%	20%
HaLo PCN	100%	20%	22%	20%	17%	20%	60%	20%	99%	20%
Harpenden PCN	75%	20%	37%	20%	43%	20%	58%	20%	100%	20%
Herts Five PCN	91%	20%	50%	20%	48%	20%	68%	20%	99%	20%
Manor View PCN	100%	20%	48%	20%	36%	20%	58%	20%	87%	20%
North Watford PCN	100%	20%	25%	20%	24%	20%	34%	20%	100%	20%
Potters Bar PCN	100%	20%	23%	20%	25%	20%	58%	20%	99%	20%
Rickmansworth & Chor	100%	20%	31%	20%	43%	20%	45%	20%	97%	20%
The Grand Union PCN	25%	20%	50%	20%	50%	20%	68%	20%	96%	20%

End of Life PCN Achievement (West Essex)

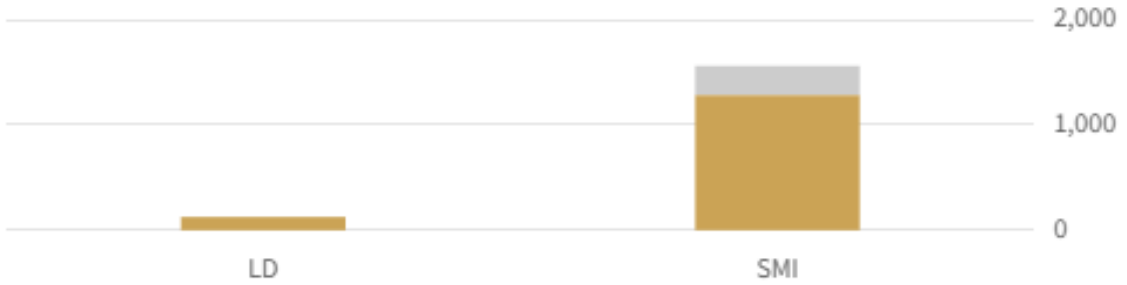
West Essex	Anticipatory medicines if GSF red/yellow		Preferred place of care recorded		Preferred place of death recorded		Resus status recorded		GSF status if severe COPD, HF, CKD or frailty	
	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold
Epping Ongar Abridge Waltham Abbey PCN	40%	20%	34%	20%	35%	20%	56%	20%	93%	20%
Harlow North PCN	56%	20%	70%	20%	71%	20%	63%	20%	95%	20%
Harlow South PCN	75%	20%	63%	20%	60%	20%	64%	20%	100%	20%
Loughton Buckhurst Hill & Chigwell PCN	49%	20%	63%	20%	61%	20%	71%	20%	100%	20%
North Uttlesford PCN	75%	20%	72%	20%	73%	20%	62%	20%	87%	20%
South Uttlesford PCN	56%	20%	50%	20%	33%	20%	63%	20%	95%	20%

Mental Health

ICB Overall Performance

Mental Health : Hertfordshire and West Essex I...

1,407.48/1,690 points achieved
(1,580/7,000 INDICATOR TARGETS REACHED)



Overall, 83% of ECF points were achieved by practices during the financial year.
Mental health indicators were streamlined at the December review to reflect winter pressures and to target the highest impact interventions. In addition the upper thresholds were reduced to 20%.
There was variation both in the delivery of different care processes as well as across practices. The largest number of points were missed on the care process related to oral health with only 44 practices achieving the threshold of 20%. However, a small number of practices overperformed on this indicator (highest performance 69%).
In comparison, all practices met the threshold of 20% for the medication reconciliation indicator, with the best performing practice achieving 96%.
There were practices that missed the thresholds of 20% across multiple indicators, with illicit substance misuse, nutrition/diet and physical activity assessment, oral health and sexual health the indicators commonly missed. There were 49 practices that did not meet the threshold of 20% across all 4 of these indicators.

Mental Health ICB Clinical Metrics

SEVERE MENTAL ILLNESS

Benchmark Hertfordshire and West Essex ICS organisations			THRESHOLDS	ACHIEVED %	POINTS	
Clinical Activity					1,281.48 / 1,560	
Core	BMI or waist circumference recorded		0 - 20%	76.98%	260 / 260	8,950 / 11,626
	BP + Pulse rate recorded		0 - 20%	57.67%	259.41 / 260	6,705 / 11,626
Extra	Illicit substance/non prescribed drug use recorded		0 - 20%	24.68%	170.44 / 260	2,869 / 11,626
	Medication reconciliation/review		0 - 20%	63.21%	260 / 260	7,349 / 11,626
	Nutrition/diet + level of physical activity in last 12m		0 - 20%	30.42%	200.27 / 260	3,537 / 11,626
Local	Oral health recorded in last 12m		0 - 20%	17.78%	63.6 / 130	2,067 / 11,626
	Sexual health recorded in last 12m		0 - 20%	17.73%	67.76 / 130	2,061 / 11,626

Mental Health PCN Achievement (Hertfordshire)

East & North Herts	BMI or waist circumference recorded		BP + Pulse rate recorded		Illicit substance/non prescribed drug use recorded		Medication reconciliation/review		Nutrition/diet + level of physical activity in last 12m		Oral health recorded in last 12m		Sexual health recorded in last 12m	
	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold
Broxbourne Alliance	76%	20%	66%	20%	66%	20%	89%	20%	67%	20%	64%	20%	61%	20%
Hatfield PCN	66%	20%	51%	20%	16%	20%	51%	20%	24%	20%	11%	20%	8%	20%
Hertford and Rurals PCN	79%	20%	43%	20%	20%	20%	46%	20%	20%	20%	6%	20%	3%	20%
Hitchin & Whitwell PCN	79%	20%	56%	20%	7%	20%	41%	20%	18%	20%	8%	20%	6%	20%
Hoddesdon and Broxbourne PCN	82%	20%	64%	20%	36%	20%	55%	20%	43%	20%	28%	20%	25%	20%
Icknield PCN	71%	20%	58%	20%	21%	20%	51%	20%	33%	20%	18%	20%	12%	20%
Lea Valley Health PCN	81%	20%	66%	20%	36%	20%	67%	20%	46%	20%	23%	20%	20%	20%
Stevenage North PCN	76%	20%	74%	20%	64%	20%	75%	20%	64%	20%	60%	20%	61%	20%
Stevenage South PCN	78%	20%	62%	20%	38%	20%	65%	20%	42%	20%	20%	20%	23%	20%
Stort Valley and Villages PCN	72%	20%	64%	20%	25%	20%	55%	20%	42%	20%	19%	20%	14%	20%
Ware and Rurals PCN	81%	20%	70%	20%	47%	20%	71%	20%	56%	20%	43%	20%	42%	20%
Welwyn Garden City PCN	76%	20%	56%	20%	33%	20%	74%	20%	36%	20%	33%	20%	33%	20%

Mental Health

PCN Achievement (Hertfordshire)

South West Herts	BMI or waist circumference recorded		BP + Pulse rate recorded		Illicit substance/non prescribed drug use recorded		Medication reconciliation/review		Nutrition/diet + level of physical activity in last 12m		Oral health recorded in last 12m		Sexual health recorded in last 12m	
	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold
Abbey Health PCN	82%	20%	64%	20%	33%	20%	54%	20%	35%	20%	13%	20%	24%	20%
Alban Healthcare PCN	76%	20%	44%	20%	14%	20%	63%	20%	14%	20%	3%	20%	5%	20%
Alliance PCN	71%	20%	40%	20%	5%	20%	56%	20%	7%	20%	1%	20%	3%	20%
Alpha PCN	81%	20%	44%	20%	25%	20%	71%	20%	23%	20%	15%	20%	17%	20%
Attenborough & Tudor PCN	83%	20%	56%	20%	4%	20%	59%	20%	11%	20%	0%	20%	3%	20%
Central Watford PCN	80%	20%	63%	20%	31%	20%	73%	20%	40%	20%	3%	20%	5%	20%
Dacorum Beta PCN	76%	20%	52%	20%	6%	20%	71%	20%	8%	20%	3%	20%	5%	20%
Delta PCN	79%	20%	50%	20%	3%	20%	64%	20%	5%	20%	4%	20%	6%	20%
HaLo PCN	76%	20%	46%	20%	1%	20%	62%	20%	14%	20%	4%	20%	12%	20%
Harpenden PCN	77%	20%	52%	20%	21%	20%	58%	20%	27%	20%	13%	20%	14%	20%
Herts Five PCN	85%	20%	73%	20%	32%	20%	69%	20%	35%	20%	26%	20%	27%	20%
Manor View PCN	74%	20%	60%	20%	24%	20%	60%	20%	24%	20%	25%	20%	23%	20%
North Watford PCN	73%	20%	62%	20%	20%	20%	86%	20%	31%	20%	1%	20%	11%	20%
Potters Bar PCN	81%	20%	53%	20%	12%	20%	68%	20%	20%	20%	3%	20%	8%	20%
Rickmansworth & Chor	79%	20%	48%	20%	18%	20%	51%	20%	16%	20%	13%	20%	17%	20%
The Grand Union PCN	87%	20%	71%	20%	27%	20%	70%	20%	33%	20%	19%	20%	18%	20%

Mental Health PCN Achievement (West Essex)

West Essex	BMI or waist circumference recorded		BP + Pulse rate recorded		Illicit substance/non prescribed drug use recorded		Medication reconciliation/review		Nutrition/diet + level of physical activity in last 12m		Oral health recorded in last 12m		Sexual health recorded in last 12m	
	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold	Achievement	Threshold
Epping Ongar Abridge Waltham Abbey PCN	86%	20%	68%	20%	39%	20%	78%	20%	47%	20%	29%	20%	24%	20%
Harlow North PCN	68%	20%	48%	20%	19%	20%	46%	20%	23%	20%	12%	20%	13%	20%
Harlow South PCN	70%	20%	59%	20%	17%	20%	52%	20%	27%	20%	6%	20%	3%	20%
Loughton Buckhurst Hill & Chigwell PCN	70%	20%	47%	20%	22%	20%	61%	20%	33%	20%	18%	20%	15%	20%
North Uttlesford PCN	81%	20%	53%	20%	15%	20%	62%	20%	14%	20%	10%	20%	11%	20%
South Uttlesford PCN	70%	20%	52%	20%	14%	20%	48%	20%	22%	20%	10%	20%	10%	20%

Procedures

Key messages

Overall, the section of the ECF that supported practices to deliver procedures and treatments resulted in significant activity that has supported primary care recovery. Of note:

- Delivery of ambulatory or home blood pressure monitoring has supported improvements in hypertension detection and management, with over 50,000 people having their blood pressure recorded by either home or ambulatory monitors. In turn, this has supported the ICS to improve:
    - 1. hypertension prevalence from 14.83% in September 2022 to 15.19% in March 2023, and;
    - 2. treatment to threshold from 61.01% to 68.29% over the same time period.
- Restarting of spirometry, supported by the ECF has resulted in over 4000 people having spirometry checks, supporting disease detection and accurate diagnosis of respiratory disease. This benchmarks very favourably compared to other systems within the region.
- Significant volumes of activity have also been recorded for ECG, ear syringing and vaginal pessary insertion/renewal.
- Whilst there was activity undertaken in practices for wound management, including dressing and suture removal, there was comparatively less activity for leg ulcer care which had the lowest levels of activity. A high proportion of practices delivered no leg ulcer care or activity was recorded on fewer than 10 people.

Procedures ICB Clinical Metrics

BLOOD PRESSURE

Benchmark Hertfordshire and West Essex ICS	organisations	THRESHOLDS	ACHIEVED %	
Clinical Activity				
All HBPM or ABPM done		-	-	51,574

ECG

Benchmark Hertfordshire and West Essex ICS	organisations	THRESHOLDS	ACHIEVED %	
Clinical Activity				
Activity Standard ECG done View		-	-	50,015

EARS

Benchmark Hertfordshire and West Essex ICS	organisations	THRESHOLDS	ACHIEVED %	
Clinical Activity				
Activity Ear syringe done		-	-	14,731

Procedures ICB Clinical Metrics

SPIROMETRY

Benchmark Hertfordshire and West Essex ICS	organisations	THRESHOLDS	ACHIEVED %	
Clinical Activity				
Activity	Spirometry done	-	-	4,275

VAGINAL PESSARY

Benchmark Hertfordshire and West Essex ICS	organisations	THRESHOLDS	ACHIEVED %	
Clinical Activity				
Activity	Ring Pessary: Insertion	-	-	751
	Ring Pessary: Renewal	-	-	940

Procedures ICB Clinical Metrics

WOUND CARE

Benchmark Hertfordshire and West Essex ICS	organisations	THRESHOLDS	ACHIEVED %	
Clinical Activity				
Leg Ulcer	Assessment	-	-	689
	Assessment + ABPI test done	-	-	192
	Management	-	-	830
Referrals	Referral to tissue viability on or after assessment	-	2.46%	17 / 692
Wound Management	Dressing of wound	-	-	23,953
	Post-op - Removal of sutures or clips	-	-	9,493

Procedures PCN Achievement (Hertfordshire)

East & North Herts	Blood Pressure	ECG	Ears	Spirometry	Vaginal Pessary		Wound Care: Leg Ulcer			Wound Care: Referrals	Wound Care: Wound Management	
	HBPM or ABPM done	Standard ECG done	Ear syringe done	Spirometry done	Ring Pessary: Insertion	Ring Pessary: Renewal	Assessment	Assessment + ABPI test done	Management	Referral to tissue viability on or after assessment	Dressing of wound	Post-op - Removal of sutures or clips
Broxbourne Alliance	1,932	1,314	407	41	16	37	41	16	38	3 / 41	614	320
Hatfield PCN	1,170	828	501	24	28	29	12	5	24	0 / 12	556	183
Hertford and Rurals PCN	2,508	794	160	18	17	44	38	6	25	0 / 38	444	202
Hitchin & Whitwell PCN	3,307	1,331	262	227	20	55	19	0	24	0 / 19	549	285
Hoddesdon and Broxbourne PCN	2,721	1,446	615	37	34	50	77	15	70	1 / 77	719	347
Icknield PCN	3,842	2,233	265	61	45	58	27	0	22	0 / 27	1,114	372
Lea Valley Health PCN	1,105	887	249	59	13	31	18	1	17	1 / 18	471	234
Stevenage North PCN	5,900	1,561	96	289	22	51	18	10	13	0 / 18	1,077	392
Stevenage South PCN	2,111	1,688	442	80	19	64	51	12	47	1 / 51	680	408
Stort Valley and Villages PCN	2,898	2,237	691	123	33	52	44	24	34	0 / 45	940	330
Ware and Rurals PCN	1,795	1,140	530	108	16	32	74	27	56	1 / 75	742	425
Welwyn Garden City PCN	1,978	1,771	518	131	32	66	16	2	10	0 / 16	691	419

Procedures

PCN Achievement (Hertfordshire)

South West Herts	Blood Pressure	ECG	Ears	Spirometry	Vaginal Pessary		Wound Care: Leg Ulcer			Wound Care: Referrals	Wound Care: Wound Management	
	HBPM or ABPM done	Standard ECG done	Ear syringe done	Spirometry done	Ring Pessary: Insertion	Ring Pessary: Renewal	Assessment	Assessment + ABPI test done	Management	Referral to tissue viability on or after assessment	Dressing of wound	Post-op - Removal of sutures or clips
Abbey Health PCN	99	838	263	140	16	14	0	0	2	0 / 0	277	98
Alban Healthcare PCN	188	720	925	219	15	15	4	2	24	0 / 4	454	163
Alliance PCN	52	230	141	93	0	3	0	0	9	0 / 0	242	98
Alpha PCN	345	1,910	531	231	57	25	1	0	10	0 / 1	1,000	328
Attenborough & Tudor PCN	54	542	5	40	6	1	0	0	3	0 / 0	446	192
Central Watford PCN	37	1,041	174	173	9	4	1	0	26	0 / 1	445	151
Dacorum Beta PCN	248	1,884	720	189	36	12	0	0	40	0 / 0	1,115	301
Delta PCN	106	1,470	626	251	17	11	2	0	28	0 / 2	608	179
HaLo PCN	248	1,446	410	303	7	14	0	0	9	0 / 0	567	209
Harpenden PCN	152	1,777	903	22	24	27	0	0	14	0 / 0	739	251
Herts Five PCN	170	1,542	518	80	26	17	0	0	18	0 / 0	1,166	339
Manor View PCN	58	1,617	221	168	14	7	1	0	7	0 / 1	464	112
North Watford PCN	65	970	78	185	9	6	0	0	32	0 / 0	284	80
Potters Bar PCN	178	761	369	65	33	17	2	0	7	0 / 2	531	160
Rickmansworth & Chor	113	1,157	137	82	3	6	0	0	13	0 / 0	387	137
The Grand Union PCN	1,310	1,841	599	38	11	16	36	6	23	0 / 36	748	305

Procedures PCN Achievement (West Essex)

West Essex	Blood Pressure	ECG	Ears	Spirometry	Vaginal Pessary		Wound Care: Leg Ulcer			Wound Care: Referrals	Wound Care: Wound Management	
	HBPM or ABPM done	Standard ECG done	Ear syringe done	Spirometry done	Ring Pessary: Insertion	Ring Pessary: Renewal	Assessment	Assessment + ABPI test done	Management	Referral to tissue viability on or after assessment	Dressing of wound	Post-op - Removal of sutures or clips
Epping Ongar Abridge Waltham Abbey PCN	3,805	2,288	549	57	19	32	55	18	46	3 / 56	1,001	476
Harlow North PCN	4,125	2,663	442	117	5	19	46	17	37	4 / 46	824	321
Harlow South PCN	2,430	1,169	211	80	11	14	24	10	19	2 / 24	532	222
Loughton Buckhurst Hill & Chigwell PCN	3,072	1,223	416	114	41	27	22	6	19	0 / 22	902	380
North Uttlesford PCN	1,036	2,051	842	92	44	13	15	3	23	0 / 15	1,156	339
South Uttlesford PCN	1,610	2,135	455	298	41	24	29	12	30	0 / 29	992	505

Hertfordshire and West Essex Integrated Care System

NHS Hertfordshire and West Essex Integrated Care Board

Meeting:	*Meeting in public*	☒	*Meeting in private (confidential)*	☐
	NHS HWE ICB Primary Care Board held in Public		**Meeting Date:**	**28/09/2023**
Report Title:	**DENTAL UPDATE – WORKPLAN AND PROCUREMENT PLAN**		**Agenda Item:**	**10**
Report Author(s):	Michelle Campbell, Head of Primary Care Contracts			
Report Presented by:	Michelle Campbell, Head of Primary Care Contracts			
Report Signed off by:	Rachel Halksworth, Assistant Director for Primary Care Contracts			
Purpose:	**Approval / Decision** ☐	**Assurance** ☐	**Discussion** ☐	**Information** ☒
Which Strategic Objectives are relevant to this report **[Please list]**	• Increase healthy life expectancy, and reduce inequality • Give every child the best start in life • Improve access to health and care services • Achieve a balanced financial position annually			
Key questions for the ICB Board / Committee:	The Board are asked to: • Note the content of the paper			
Report History:	N/A			
Executive Summary:	This paper provides an update to the Board on the dental workplan as presented at the last meeting in July. The paper reports on the final 2022-23 year end contract performance across several service lines and how the team will seek to improve this position for the 2023-24 year end. Areas for update include areas being addressed to reduce health inequalities or gaps in provision; including the development of the Special Care Dental Service specification and other supplementary services such as sedation and minor oral surgery. The paper also outlines areas of dental transformation that have been identified for progression over the next 12 months			
Recommendations:	The Board is asked to note the content of the paper			
	Indirect	☐	***Non-Financial Professional***	☐

Potential Conflicts of Interest:	***Financial***	☐	***Non-Financial Personal***	☐
	None identified			☒
Implications / Impact:				
Patient Safety:	Patient Safety Issues will be addressed within any business case that is developed for approval.			
Risk: *Link to Risk Register*	N/A			
Financial Implications:	Any financial implications will be identified in any business case that is developed for approval.			
Impact Assessments: *(Completed and attached)*	***Equality Impact Assessment:***		N/A	
	Quality Impact Assessment:		N/A	
	Data Protection Impact Assessment:		N/A	

Hertfordshire and West Essex Integrated Care System

NHS
Hertfordshire and West Essex
Integrated Care Board

PRIMARY CARE CONTRACTS - DENTAL UPDATE

Presentation to:
Primary Care Commissioning Committee

Tuesday 28th September 2023

Working together
for a healthier future

Updates on the Dental Workplan

This paper provides the Board with an update on the dental workplan for the following areas:

- 2022-23 Contract Performance
- Dental Access
- Special Care Dental Services Development
  - Bariatric Chair
  - Screening in Care Homes
  - Anxious Children
  - Piloting alternative therapies
- Supplementary Services
  - Dental Referral Management Service
  - Level 1 Sedation
  - Level 2 Minor Oral Surgery
- Dental Transformation Areas

2022-23 Contract Performance

- Each year the national general dental and orthodontic contracts allow for a 4% tolerance for under-delivery
- 2022-23 the tolerance for general dental services was increased to 10% to account for challenges dental contractors were experiencing due to the pandemic; therefore no contract sanctions were implemented where general dental services contracts delivered 90% or more
- The average delivery across england was between 80 – 90%; in HWE 86.3% was delivered overall which was the highest in the region

Service Line	Annual Contracted Activity 2022-23	2022-23 Contract Delivery %	Annual Contracted Activity 2023-24	2023-24 Contract Delivery YTD* %
General Dental	2,166,099	87.25%	2,144,357	33.80%
Orthodontic	169,178	99.72%	169,178	36.5%
Domiciliary	1,600 CoT**	31.88%	1,600	13.09%
Sedation	6,044 CoT**	80.41%	6,044	
Minor Oral Surgery (contracts are paid on activity delivered)	N/A	11,267	N/A	5,108

*Data up to 22 August 2023
**CoT = Courses of Treatment

- The Special Care Dental Service (SCDS) contract is based on the number of contacts seen and GAs/Sedations provided; however activity is recorded as UDAs within the NHSBSA system. The service has seen an increase of 84% in referrals with an acceptance rate of 47%

Dental Access

- The GP Patient survey includes a question regarding the success of getting an NHS Dental appointment in the last 2 years
    - HWE ICB was in the top 3 ICBs with 82% behind NHS Mid and South Essex (83%) and NHS Coventry and Warwickshire (87%) of respondents indicating they were successful in getting an appointment.
    - Out of all the respondents who indicated they **didn't** try to get an NHS dental appointment, 32% said they preferred to see a private dentist and 21% said they didn't think they could get an NHS dentist.
- Following the 2022-23 year end position; the team will continue to work with contractors to maximise the delivery of their contracts by taking on new patients.
    - Discussions with contractors who repeatedly under-perform year on year on permanently re-basing their contract to enable the re-commissioning of this activity within other local contracts
- We are developing an "Enhanced Access Scheme" for dentistry to pilot over winter; this will provide access to urgent, same day appointments 7 days a week, including bank holidays. We are aiming to launch this in October following consideration at the Primary Care Commissioning Committee.

Special Care Dental Service (SCDS) Development

- **Bariatric Dental Chair** – Funding for up to 3 mobile bariatric chairs agreed, to be installed within the Hertfordshire SCDS clinics in Hemel, Letchworth and Cheshunt (close to WE borders). Provider is currently working with their Estates team to ensure the Cheshunt Clinic can accommodate these patients in the surgery is on the first floor. WE practices can currently refer patients to the clinic in Colchester which not all patients can travel to.

- **Domiciliary in Care Homes** – Activity is low within the Hertfordshire contract due to patients not consenting to treatment due to the patient charge. Therefore we have agreed to flex a proportion of the contract to enable the provider to undertake some screening and oral health promotion sessions within these settings; including the application of fluoride varnish.

- **Anxious Children** – Due to the increase in rejected referrals from out of area trusts, we have agreed funding on a case by case basis for the Hertfordshire SCDS provider to see anxious children to ensure they have access to services in a timely manner. In the meantime, we are working with the provider to develop a more appropriate specification to include an anxiety management pathway which is linked in to the sedation pathway.

- **Piloting "alternative therapies"** – HWE ICB are soon to commence a pilot ran by St Guys and Thomas' NHS Hospital Trust in the use of alternative therapies to reduce the need for sedation or referrals into secondary care; the London pilot reported a substantive positive impact and cost savings by using CBT techniques.

- **Epidemiology Survey 2023-24** – these surveys are usually commissioned by the local authority and embedded within the SCDS Contract to deliver these. However in Hertfordshire this was not commissioned from the SCDS and therefore we have sought additional approval for funding to participate in this survey which will focus on Year 5 children within 20 schools from a Lower Tier or Unitary Authority. This programme will commence in January 2024.

Supplementary Services

Dental Referral Management Service

- There are 2 contracts across the ICB for a dental referral management service; one for Herts and BLMK and the other across Essex. These contracts are held with the same provider however are not consistent in the service they deliver:
  - In Hertfordshire, all dental referrals are sent via the RMS
  - In Essex, only Oral Surgery referrals are sent via the RMS

- The Primary Care Contracting Panel agreed for both contracts to include all 2WW referrals to be managed by the RMS and in addition, Orthodontic referrals in West Essex; to ensure consistency on the management of referrals across the ICB.

Level 1 Sedation Services

- Review of the 4 sedation services across HWE underway to develop the pathway further to align sedation providers with the SCDS for training and peer support to manage anxious patients more effectively; taking the learning from the pilot for ‘alternative therapies” as highlighted in the previous section

Level 2 Minor Oral Surgery

- Planned review of services to ensure current provision is meeting the needs of the population

Dental Transformation Areas and Timelines

The following table identifies areas of transformation that will address health inequalities and gaps in provision that have been identified throughout this paper. Performance metrics will be presented as part of the Primary Care Dashboard; which will include both activity and waiting times across community and secondary care pathways.

Transformation Area	Action	Timeline
Review of the current SCDS Contracts across Herts and west Essex	To develop a more effective and robust specification with key performance indicators to bridge the gaps in the current contract and build on addressing health inequalities of the population. This will include developments in the sedation pathways	April 2024
Dental Access for Asylum/Migrants	To commission dental support for Asylum/Migrant Seekers including initial assessment of oral health needs and necessary treatment when placed within ICB boundary. This will be provided as in-reach into the various settings with referrals into “centres” for the delivery of treatment.	December 2023
Increase Dental Access	- Currently developing a specification to pilot an “enhanced dental access scheme” to support urgent, same day access both in and out of hours. - Working in partnership with local providers and the Local Dental Committees to scope out how to increase capacity and provide innovation/collaboration with SCDS i.e. anxiety management pathway	October 2023 January 2024
Domiciliary Care – housebound and residential and nursing homes	To develop a domiciliary specification for primary dental practices to see housebound patients; supported by the SCDS working with residential and nursing home residents.	April 2024
Secondary Care Dental Pathways	Working collaboratively with the acute trusts, Local Dental Network and Dental Managed Clinical Networks to develop primary/secondary care integrated pathways.	April 2024
Level 1 Endodontic and Periodontal Services and the EoE Trauma Pathway	Have oversight of the current evaluations of these pilot services to understand the opportunity for commissioning these within HWE ICB.	April 2024

Questions?

Hertfordshire and West Essex Integrated Care System

NHS Hertfordshire and West Essex Integrated Care Board

Meeting:	*Meeting in public*	☒	*Meeting in private (confidential)*	☐
	NHS HWE ICB Primary Care Board meeting held in Public		**Meeting Date:**	**28/09/2023**
Report Title:	**Reports from Healthwatch Hertfordshire –** **1. Report and Recommendations on Autistic People's Experiences of Accessing GP Services** **2. Report and Recommendations on Accessing Support from Primary Care Services for the Menopause**		**Agenda Item:**	**13**
Report Author(s):	Asha McDonagh, Research Officer, Healthwatch Hertfordshire Miriam Blom-Smith, Research Officer, Healthwatch Hertfordshire Chloe Gunstone, Senior Research Manager, Healthwatch Hertfordshire Geoff Brown, Chief Executive, Healthwatch Hertfordshire			
Report Presented by:	Chloe Gunstone, Senior Research Manager, Healthwatch Hertfordshire (on behalf of Neil Tester, Co-Chair, Healthwatch Hertfordshire who has a Board event on this date)			
Report Signed off by:	Avni Shah, Director of Primary Care Transformation, Hertfordshire and West Essex ICB			
Purpose:	**Approval / Decision** ☐	**Assurance** ☐	**Discussion** ☒	**Information** ☐
Which Strategic Objectives are relevant to this report **[Please list]**	▪ Increase healthy life expectancy and reduce inequality ▪ Improve access to health and care services			
Key questions for the ICB Board / Committee:	▪ How can GPs be made more aware of the menopause and its impact, particularly for women who are not in the usual age bracket for the menopause? ▪ How can GP surgeries and processes better address the varied needs of autistic patients? ▪ How can GP surgeries build the provision of autism and neurodivergence awareness training for all clinical and non-clinical			

	into Customer Care Training, so that all staff can provide better awareness of and support to these patient groups?
Report History:	N/A
Executive Summary:	Between May and August 2023, Healthwatch Hertfordshire carried out engagement exploring the following: ▪ Autistic People's Experiences of Accessing GP Services ▪ Accessing Support from Primary Care Services for the Menopause **<u>Autistic People's Experiences of Accessing GP Services</u>** **131** autistic adults completed our online survey. A further **6** people took part in a one-to-one interview – these participants were either autistic themselves or a parent/carer or an autistic person. This engagement aimed to understand the experiences of autistic people when accessing GP services, and to learn how GP practices could be more autism-friendly. Although nearly half of all autistic people responding said the support they received from their GP was good, it is clear that autistic people face many additional barriers to healthcare and generally find accessing GP services incredibly distressing, such that some were prevented from accessing care entirely. Key themes included: ▪ Significant difficulties when making an appointment, often causing greater distress. ▪ Lack of choice, including appointment times, types of appointments, and seeing the same GP. ▪ Lack of understanding from reception staff and in some cases, rude and unkind behaviour. ▪ Significant barriers when visiting their GP practice for an appointment, again often causing stress and anxiety. ▪ Poor care, treatment and communication from clinicians. ▪ The need for greater training, awareness and understanding of autism and neurodivergence amongst clinical and non-clinical staff. ▪ Lack of awareness and provision of reasonable adjustments, despite the important role they play in improving access and patient experience. ▪ Good practice included: kind, understanding and accommodating clinicians and reception staff, the provision of reasonable adjustments, and patient choice. **<u>Accessing Support from Primary Care Services for the Menopause</u>** **560** women completed our online survey. This engagement aimed to understand the barriers women face in accessing support from primary

	care services for the menopause, and to learn what information, care and treatment women want during the menopause. Although most women had accessed support from primary care services, the quality of care received varied significantly. Some women felt listened to and received immediate support, while others felt dismissed and not taken seriously and as such, often did not receive the support they needed and/or in a timely manner. Key themes included: ▪ Barriers to accessing support, including understanding of symptoms, difficulties accessing NHS services, belief that they would not be appropriately supported or taken seriously. ▪ Lack of information, knowledge and awareness of menopausal symptoms amongst women. ▪ Delays in diagnosis and treatment. ▪ Poor care and treatment from clinicians, dismissing symptoms and not listening to the patient's needs. ▪ Younger women tended to face greater barriers and poor treatment from clinicians. ▪ Need for more training, greater empathy and understanding amongst clinical staff, information about menopausal symptoms, signposting, and personalised care. ▪ Good practice included clinicians who listened, provided empathy and support, offered a range of treatment options, and adopted a holistic approach.
Recommendations:	**<u>Autistic People's Experiences of Accessing GP Services</u>** It is recognised that general practice is facing significant pressure. However, it is important that people who are already at a disadvantage, such as autistic people, do not suffer more as a consequence of these pressures on services. Recommendations focus on the following themes: identification, reasonable adjustments, communication, training and awareness, and autism health checks. **<u>Identification</u>** 1. Support the implementation and promotion of the 'digital flag' for autistic people to add to patient records that indicate their eligibility for reasonable adjustments and enable the GP to be aware of the diagnosis. 2. Reception staff should be proactive in reading patient records and checking whether any additional support is needed. **<u>Reasonable adjustments</u>** 3. Ensure that all GP practices are proactive in offering reasonable adjustments and are making patients aware of their right to ask for them. Any support requested must be implemented and not denied. Of particular importance are:

- Longer or double appointments
- Appointments at less busy times
- A quiet or private place to wait
- Ability to see their named GP
- Ability to choose the type of appointment they have
- Ability to bring someone to support them at their appointment

Communication

4. As stated under the Accessible Information Standards (2016) clinicians should ensure they are communicating with autistic people in a way that is accessible to them, providing information in a range of formats.

Flexibility of Appointments

5. Improve flexibility in the methods available to make an appointment to take into account individual needs and preferences – there should always be more than one way to book an appointment.

Training and awareness

6. Ensure the provision of autism and neurodivergence awareness training for all clinical and non-clinical staff working in GP practices.
7. Clinical staff should take a holistic approach when interacting with patients, examining both their physical health as well as their emotional wellbeing.
8. Clinical and non-clinical staff should treat autistic people with respect, dignity and understanding, and play a proactive part in supporting autistic people to communicate their needs and concerns.

Autism health checks

9. Continue to pilot Autism Health Checks across GP practices in Hertfordshire, and find out from autistic people what works well, what could be better, and what checks should be included.

Accessing Support from Primary Care Services for the Menopause/Perimenopause

It is recognised that primary care services are under immense pressure, however it is important that women are appropriately supported by these services during the perimenopause/menopause. Recommendations focus on the following themes: information, training, communication, support, and access.

Information

1. Providing information and resources (such as posters and leaflets) in GP practices and on GP practice websites, outlining the signs of

the menopause and what support NHS healthcare providers can offer. Leaflets and posters could also be provided in pharmacies to extend the reach.
2. Signposting to local and national groups and charities supporting women during the menopause by providing information and resources in GP practices, pharmacies and on GP practice websites.

Training

3. Clinical staff should receive more training, information and education on the menopause.
4. Every GP practice should work towards having a healthcare professional who specialises in the menopause/women's health.
5. If a GP practice has a clinician who specialises in this area, this should be signposted to on the GP practice website and mentioned to patients requesting an appointment about menopausal symptoms.

Communication

6. Clinicians should assess women if they come in with symptoms of the menopause, no matter what age they are.
7. Clinicians should take young women seriously, offering them blood tests when they come in with menopause symptoms.
8. Clinicians should treat women going through the menopause with kindness, respect, and take their concerns and symptoms seriously. Clinicians should be particularly mindful when discussing potential menopausal symptoms with younger women.

Support

The following recommendations indicate what good practice looks like. However, it is recognised that healthcare providers are facing challenges and under pressure.

9. Clinicians should provide care that is personalised and specific to the individual.
10. Clinicians should take a more holistic approach to treating the menopause, taking into account the patient's physical, psychological and social needs.
11. Clinicians should provide a wider range of treatment options, enabling women to choose what medication and/or treatment is right for them.
12. Clinicians should signpost patients to local and national groups/charities supporting women during the menopause/perimenopause.
13. Clinicians should discuss the menopause at routine check-ups and NHS Health Checks.

Access

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<tr><td></td><td colspan="4">14. Continuing to improve telephone systems to reduce delays and waiting times.
15. Offering greater flexibility in contact hours and opening hours to account for people who work and/or having caring responsibilities.
16. Offering greater choice in appointment types to enable patients to get the support they want and need.</td></tr>
<tr><td rowspan="4">Potential Conflicts of Interest:</td><td>Indirect</td><td>☐</td><td>Non-Financial Professional</td><td>☐</td></tr>
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Autistic People's Experiences of GP Services in Hertfordshire

Engagement: May – July 2023

Published: XXX

Authors:
Miriam Blom-Smith and Chloe Gunstone

healthwatch Hertfordshire

Contents

About Healthwatch Hertfordshire

Healthwatch Hertfordshire represents the views of people in Hertfordshire on health and social care services. We provide an independent consumer voice evidencing patient and public experiences and gathering local intelligence to influence service improvement across the county. We work with those who commission, deliver and regulate health and social care services to ensure the people's voice is heard and to address gaps in service quality and/or provision.

About the Hertfordshire and West Essex Integrated Care System

The Hertfordshire and West Essex Integrated Care System (ICS) was established as a statutory body on 1st July 2022. Integrated Care Systems are geographically based partnerships that bring together providers and commissioners of NHS services with local authorities and other local partners to plan, coordinate and commission health and care services[1]. The Hertfordshire and West Essex ICS is made up of two key bodies – an Integrated Care Board (ICB) and Integrated Care Partnership (ICP).

Integrated Care Board (ICB)

The Integrated Care Board (ICB) is an NHS organisation responsible for planning and overseeing how NHS money is spent across Hertfordshire and West Essex, with the aim of joining up health and care services, improving health and wellbeing, and reducing health inequalities. The board of the ICB includes representation from NHS trusts, primary care and from Hertfordshire County Council and Essex County Council[2].

This report will be sent to the Hertfordshire and West Essex ICB Primary Care Board to inform how it can further support people to look after their heart health.

Integrated Care Partnership (ICP)

The Integrated Care Partnership (ICP) is made up of representatives from different organisations involved in health and care. This includes NHS organisations, local authorities and the Voluntary, Community, Faith and Social Enterprise (VCFSE) sector. The partnership is responsible for developing an Integrated Care Strategy which will set out the priorities for Hertfordshire and West Essex for the next 10-20 years[3].

[1] Integrated care systems: how will they work under the Health and Care Act? | The King's Fund (kingsfund.org.uk)
[2] Health and wellbeing decisions – Hertfordshire and West Essex Integrated Care System (hertsandwestessexics.org.uk)
[3] Health and wellbeing decisions – Hertfordshire and West Essex Integrated Care System (hertsandwestessexics.org.uk)

Hearing Patient Views about Primary Care in Hertfordshire and West Essex

Healthwatch Hertfordshire and Healthwatch Essex have been commissioned by the Hertfordshire and West Essex Integrated Care Board (ICB) Primary Care Workstream to undertake a series of engagement projects. The aims of the engagement projects include:

- Gathering lived experiences to feed directly into the Hertfordshire and West Essex ICS Primary Care Workstream
- Supporting and enabling the Hertfordshire and West Essex ICS to achieve wider participant engagement
- Engaging patients and the public on programmes covering key priorities and areas of importance at a regional and local level
- Making recommendations to the Hertfordshire and West Essex ICS Primary Care Workstream so improvements can be implemented

Using patient and public feedback, this engagement project will focus on improving the relevant services within different areas of primary care by making recommendations to the Hertfordshire and West Essex ICB Primary Care Board.

From May to August 2023, the Director of Primary Care Transformation at the ICB has requested that Healthwatch Hertfordshire explore autistic people's experiences of GP services, with a focus on[4]:

- Their experiences of contacting and visiting their GP practice, and the challenges they may face when accessing their GP practice
- Their awareness of reasonable adjustments and whether GP practices support in offering and implementing reasonable adjustments
- Whether autistic people feel understood by reception staff and healthcare professionals within their GP practice
- What GP services are currently doing to support autistic people
- How GP services could improve to better meet the needs of autistic people

[4] The term 'autistic people' has been used throughout this report as the preferred term for most autistic people, in accordance with research and guidance from the National Autistic Society: https://dy55nndrxke1w.cloudfront.net/file/24/xT2FqU_xTh5_JA5xTMYZxb.dfV0x/NAS_How%20to%20talk%20and%20write%20about%20autism.pdf

Background

Autism

> *"Autism is a lifelong developmental disability which affects how people communicate and interact with the world. More than one in 100 people are on the autism spectrum and there are around 700,000 autistic adults and children in the UK."*
>
> - National Autistic Society[1]

The signs and characteristics of autism can vary greatly between people - every individual will have a different profile from a wide range of traits and range of severity. Nevertheless, in addition to their individual strengths, there are some shared difficulties that autistic people may face that can be helpful in understanding and identifying autism. These include: social communication and social interaction challenges, repetitive and restrictive behaviour, over- or under-sensitivity to light, sound, taste or touch, highly focused interests or hobbies, extreme anxiety, and meltdowns and shutdowns. Not every autistic person will experience these, and many autistic people will also face other challenges not listed[5]. It is also common for autistic people to experience co-occurring conditions such as ADHD, dyslexia, dyspraxia, insomnia, mental health problems, learning disabilities, epilepsy and hypermobility. Autistic people will therefore also have varying needs in terms of education, healthcare and overall support in day-to-day life.

Healthcare

Currently, autistic people have poorer health outcomes and on average, die 16 years earlier than non-autistic people[6], with suicide being a leading cause of death. Autistic people are less likely to identify and seek help for health problems, meaning they often present late with healthcare needs. Further to this, poor or inconsistent understanding of autism amongst healthcare staff can mean that signs and symptoms of illness are missed, and autistic people are more likely to have to use emergency services when a crisis point has been reached[7].

Autistic people also often have different responses to pain and can have difficulty identifying emotions[8]. As such, diagnosing health conditions in autistic people can be difficult, particularly when there is a broad range of co-occurring conditions. When these factors are coupled with mutual miscommunication, serious symptoms can be unnoticed, dismissed or underestimated and can mean that treatment is prolonged or complicated.

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[5] What is autism

[6] The national strategy for autistic children, young people and adults: 2021 to 2026 (publishing.service.gov.uk)

[7] Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf

[8] Increased pain sensitivity and pain-related anxiety in individuals with autism - PMC (nih.gov)

In healthcare, unfortunately it is typically the case that autistic people's needs are not sufficiently met, or that, for a multitude of reasons, they face barriers in accessing the right healthcare for them[9]. Research from 2022 found that 80% of autistic people faced difficulties when visiting a GP, in comparison to 37% of non-autistic respondents. The most common barrier cited was deciding whether symptoms required a GP visit (72%), followed by having difficulties using the telephone to make an appointment (62%). In the same research, just 16% of non-autistic respondents reported that they had particular difficulty using the telephone system[10]. Other factors, also experienced by over half of autistic respondents were not feeling understood by their doctor, having difficulty communicating with their GP and trouble with the waiting room environment. The research found that, as a result of these barriers, autistic people experienced adverse outcomes such as untreated mental or physical health conditions, late presentation to specialist referral or screening programmes and life-threatening conditions going untreated. 60% of respondents from the study were told that they should have attended primary care sooner[11].

Mental health

Not only do autistic people have poorer physical health outcomes, they are also more likely to experience mental health problems, and more likely to die by suicide. They are recognised as a high-risk group by the 2018 NICE guidelines on suicide prevention[12]. Just 1% of people in the UK are diagnosed autistic, whereas 11% of people who die by suicide are autistic[13]. It is thought that mental health problems among autistic people could, in part, be because they are more likely to experience social isolation, unemployment, trauma, and abuse. Further to this, as highlighted, autistic people are more likely to face barriers to timely and appropriate healthcare, including mental health care, meaning they miss out on preventative measures[14].

Parents and Carers

It has been evidenced that parents go through high levels of stress and intense emotion during an autism diagnosis for their child, and that difficult relationships between parents and healthcare professional are often continued beyond diagnosis[15].

Parents and carers of autistic people are often required to advocate for their child in the healthcare system and are often frustrated by their experiences. Research has shown that parents also experience poor communication from healthcare professionals, in addition to

[9] https://www.autism.org.uk/advice-and-guidance/professional-practice/research-gps

[10] Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study | BMJ Open
[11] Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study | BMJ Open
[12] Preventing suicide in community and custodial settings (nice.org.uk)
[13] Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf
[14] Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf
[15] A meta-synthesis of how parents of children with autism describe their experience of advocating for their children during the process of diagnosis - Boshoff - 2019 - Health & Social Care in the Community - Wiley Online Library

feeling like they don't have a voice in their child's care. Furthermore, many parents feel that health care professionals do not have an individualised approach, perhaps due to lack of understanding about autism[16]. Many parents said their experience of healthcare services with their children would be improved if they were able to be more involved in a collaborative way with doctors, as experts on their child[17].

General Practice

General Practitioners (GPs) are the first port of call for any non-urgent health need, so they are in a position to support their autistic patients with their overall health, and refer them to specialist providers where necessary. However, evidence suggests that many GPs have not received any training on autism, and those without any experience of autism in their personal lives do not feel very confident in their ability to support their autistic patients[18]. There are also other factors to consider such as system-level barriers and what the role of the GP is in identifying and supporting autistic patients. Ultimately, research currently suggests that many autistic people are unable to visit their GP, or do not have a good, or even acceptable experience when they do go[19]. A lack of identification, awareness and understanding also means that necessary reasonable adjustments are not being put in place to ensure autistic people are able to access the right medical care.

Statutory responsibilities

Many autistic people have sensory needs such as sensitivity to light and sound that make visiting GP surgeries distressing and anxiety inducing, and these are often not mitigated or addressed[20]. Other sensory differences for autistic people include touch sensitivity and sensory or information overload[21]. They will also often have specific communication needs, which is particularly important when interacting with healthcare professionals.

The 2010 Equality Act dictates that the NHS puts reasonable adjustments in place for people with disabilities to ensure that they have equal access to healthcare. Examples of reasonable adjustments that autistic people might need in healthcare environments are:

- Quiet waiting room
- Flexibility in appointment times
- Communication support
- Longer or double appointments
- Continuity or choice of practitioner

[16] A meta-synthesis of how parents of children with autism describe their experience of accessing and using routine healthcare services for their children - Boshoff - 2021 - Health & Social Care in the Community - Wiley Online Library
[17] A meta-synthesis of how parents of children with autism describe their experience of accessing and using routine healthcare services for their children - Boshoff - 2021 - Health & Social Care in the Community - Wiley Online Library
[18] Supporting GPs working with autistic patients (autism.org.uk)
[19] Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study | BMJ Open
[20] NHS England — Midlands » NHS helps to create sensory-friendly GP surgeries to support autistic people
[21] Sensory differences - a guide for all audiences (autism.org.uk)

- Choice of communication method
- Ability to have a parent/carer/friend present

Reasonable adjustments should be anticipatory, meaning that the service should be aware of, and put in place, the reasonable adjustments somebody needs prior to their appointment. This requires that GP surgeries include the individual requirements of their patients in their patients' records[22].

It is also legally required that NHS and social care providers follow the Accessible Information Standard (2016). This legislation commits to "identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss."[23] The standard requires NHS providers to[24]:

- Ask people if they have any information or communication needs, and find out how to meet their needs.
- Record those needs clearly and in a set way.
- Highlight or 'flag' the person's file or notes so it is clear that they have information or communication needs and how those needs should be met.
- Share information about people's information and communication needs with other providers of NHS and adult social care, when they have consent or permission to do so.
- Take steps to ensure that people receive information which they can access and understand, and receive communication support if they need it.

Autistic people's communication needs vary to a great extent, but many autistic people will have difficulty communicating effectively with their GP, particularly if they are unfamiliar or the environment is difficult. It is therefore especially important that healthcare professionals understand each autistic patient's needs and requirements so that both parties are giving and receiving important health-related information in a way that is mutually helpful.

Despite these two legal requirements being in place, many autistic people are still experiencing unequal and life-shortening obstacles when accessing healthcare[25].

National Strategy

In 2021, the Government published '*The national strategy for autistic children, young people and adults: 2021 to 2026'.* This strategy follows several previous strategies dating back to the Autism Act 2009. The 2021 document sets out a vision for the years 2021-2026, and includes several priorities to improve autistic people's lives, one of which is 'tacking health and care

[22] Reasonable Adjustment Flag - NHS Digital
[23] NHS England » Accessible Information Standard
[24] NHS England » Accessible Information Standard comes into force
[25] Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf

inequalities'[26]. As part of this, in addition to tackling diagnostic waiting times, the strategy aims to improve support and healthcare following diagnosis.

In the Health and Care Act 2022, the Oliver McGowan Mandatory Training on Learning Disabilities and Autism became mandatory for health and social care staff. It was developed after the avoidable and untimely death of an autistic person due to a lack of awareness and understanding from the staff caring for him. This training aims to ensure that the "health and social care workforce have the right skills and knowledge to provide safe, compassionate and informed care to autistic people". With the training now mandatory, it is hoped that it will help to support healthcare professionals and support staff to offer more personalised, appropriate, and safer care to their autistic patients.

The 2021 document also commits to developing a better understanding of autistic people's experiences of healthcare. It also plans to develop and trial programmes such as autism health checks that are intended to improve autistic people's health, with the organisation Autistica partnering with NHS England to ensure every autistic adult receives an annual health check by 2030[27] and in Hertfordshire, autism health checks have started to be piloted in a selection of GP practices. Another key priority in this strategy is the development of 'digital flags' on patient records, to enable healthcare professionals to better tailor their support to the needs of their autistic patients.[28]

Local picture

It is evident that there are huge nationwide problems in healthcare for autistic people, leading to them experiencing a health inequalities gap. Steps are being taken to better support autistic people, but it will still take more time, commitment, and willingness to learn and adapt, in order to reach our shared healthcare goal for the autistic community.

In 2020, there were estimated to be over 8900 adults with Autism Spectrum Disorder living in Hertfordshire[29]. However, in 2015 there were just 2,615 people recorded on GP registers as being autistic, indicating a huge gap in the knowledge of GP practices. This severely limits their capacity to support and treat their autistic patients in a suitable way, with reasonable adjustments and considerations. By 2025, it is estimated that the number of autistic adults in Hertfordshire will have risen to over 9600 and this number is only likely to increase[30]. In terms of children and young people, in 2020, the rate of autistic children known to schools was 16.7 per 1,000. This does not include those who are waiting for a formal diagnosis, so the number is likely to be higher still[31].

[26] The national strategy for autistic children, young people and adults: 2021 to 2026 (publishing.service.gov.uk)
[27] Health-Checks-Plan.pdf (autistica.org.uk)
[28] The national strategy for autistic children, young people and adults: 2021 to 2026 (publishing.service.gov.uk)
[29] autism-spectrum-disorder-jsna.pdf (hertfordshire.gov.uk)
[30] https://www.hertshealthevidence.org/microsites/jsna/jsna-documents/autism-spectrum-disorder-jsna.pdf
[31] https://www.hertshealthevidence.org/microsites/jsna/jsna-documents/autism-spectrum-disorder-jsna.pdf

Aims of the Research Project

- To explore the experiences of autistic people when contacting and visiting their GP practice
- To understand the barriers that autistic people face when accessing their GP practice, and the impact of these barriers on them
- To identify whether autistic people are aware of reasonable adjustments, and if this support is being offered and/or implemented by their GP practice
- To understand whether autistic people feel understood by reception staff and/or healthcare professionals within their GP practice
- To consider parent/carer perspectives on navigating GP services for the autistic person they care for
- To explore any improvements GP practices could make to be more autism-friendly, from the perspective of autistic people

Methodology

The aims of this research were explored through an online survey for autistic adults to complete, although this was sometimes completed with the support of a parent or carer. This methodology was chosen in order to be sensitive to communication preferences and to reach a greater number of participants. People who completed the survey were given the option to leave an email address and be contacted for an interview should they wish. The survey was also available in different formats, but this was not requested at any point.

To support the survey, we also offered interviews with the parents and carers of autistic children and adults. This approach meant that we captured the experiences of children, in addition to parents and carers' perspectives on GP services.

The engagement period for the online survey ran from May - July 2023. The survey was promoted via social media and shared with the NHS, other statutory services, and the Voluntary, Community, Faith and Social Enterprise sector across Hertfordshire to distribute via their networks, contacts and social media channels. These stakeholders also received a digital flyer to support with promotion.

Key Findings

Most respondents found accessing GP Services to be very **stressful**, **difficult** and to cause great **distress** and **anxiety**, meaning some avoided it altogether or did not benefit from their appointment.

The **barriers** respondents commonly faced included:

- Not being able to contact the practice through a communication method suitable for them.
- Feeling dismissed or treated rudely by reception staff.
- Finding waiting areas incredibly difficult environments, which increased anxiety prior to an appointment.
- Experiencing significant anxiety from waiting itself, either on the phone or in-person, which often contributed to communication difficulties at the appointment.
- Not being supported with, or even being refused reasonable adjustments such as longer appointments, seeing a familiar clinician or a choice of appointment type.
- Experiencing a lack of kindness, patience and understanding from both clinical and non-clinical staff, meaning that respondents felt rushed, like a nuisance, or not safe to express their needs.
- A lack of awareness and knowledge of autism from clinical staff, such that respondents felt misunderstood and that the care they receive was not suitable or appropriate to their needs.

Some respondents did share examples of **good experiences** of GP Services, where particular members of staff had been especially kind and accommodating, which made a significant difference to their experience. Others said that they had received **reasonable adjustments**, and that these had a positive impact on how they were able to manage making and attending an appointment.

66%
were not aware of the reasonable adjustments they're entitled to

48%
didn't feel very or at all understood by their GP

69%
said they would benefit from an Autism Health Check

Demographics:

Overall, this research heard from **131** autistic people via a survey, and a further **6** people via interview, who were either autistic themselves, or a parent/carer of an autistic person. The survey was also filled in by parents/carers on behalf of an autistic person they care for.

Age:

- 18-24 years: **24%**
- 25-34 years: **18%**
- 35-44 years: **18%**
- 45-54 years: **18%**
- 55-64 years: **9%**
- 65-74 years: 1**%**
- 75+ years: 1**%**
- I'd prefer not to say: 9**%**

Gender:

- Male: **46%**
- Female: **44%**
- Non-binary: **1%**
- I'd prefer not to say: **5%**
- Other: **3%** (1 transwoman, 1 transman, 1 trans man/non-binary)

Ethnic background:

- White: British/English/Northern Irish/Scottish/Welsh: **71%**
- I'd prefer not to say: **9%**
- White: Irish: **4%**
- White: Any other White background: **3%**
- Black/Black British: African: **2%**
- Mixed/Multiple ethnic groups: Black Caribbean and White: **2%**
- Mixed/Multiple ethnic groups: Any other mixed/multiple ethnic backgrounds: **2%**
- Asian/Asian British: Indian: **1%**
- Asian/Asian British: Pakistani: **1%**
- Asian/Asian British: Any other Asian/Asian British background: **1%**
- Black/Black British: Caribbean: **1%**
- White: Polish: **1%**

Other:

- Are a carer: **26%**
- Have a disability: **54%**
- Have a long-term condition: **40%**
- None of the above: **3%**
- I'd prefer not to say: **9%**

Please see appendices for number of survey respondents per GP Practice

All Findings

Overall support

When asked to describe the overall support respondents received from their practice:

42% said it was good or very good
34% said it was neither good nor bad
24% said it was bad or very bad

Examples of positive experiences included:

- Clinicians being friendly, patient and understanding.
- Provision of reasonable adjustments e.g. quiet waiting rooms, well signposted
- Feeling listened to
- Accommodating of their individual needs.
- Able to see the same clinician/continuity of care

Examples of negative experiences included:

- Lack of understanding
- Rude and unkind reception staff and clinicians
- Poor care and treatment
- Lack of choice - appointment times, type of appointment, seeing the same GP
- Lack of reasonable adjustments
- Poor communication from clinicians

Respondents choosing neither good nor bad could be a result of limited interaction with their GP practice due to access difficulties or barriers. Many will also have their parent or carer supporting them, which might improve their experience.

Whilst these statistics are an initial indication of findings and show that some GP practices are providing good support to autistic people, the remainder of the report presents individual's thoughts and experiences in more detail as to both what their GP practice is doing well, and what improvements need to be made.

GP Patient Records

64% of respondents said that their GP practice knows that they are autistic. **13%** said their GP practice does not know, and **22%** were unsure.

Of the **64%**, the majority **(47%)** said that this does not improve their experience of accessing their GP practice in any notable way, and **30%** were not sure if it did.

For those whose experience it did not improve, this was sometimes due to inconsistent knowledge amongst reception staff and clinicians, and confusion as to whether or not their autism has been flagged on their patient records.

"I don't think they even read and acknowledge the individual notes of their patients. So they just treat him like any other patient. Never once have I felt like my child's needs have been noted."

"They seem not to pay attention or take that into consideration during appointments, causing access barriers."

Others felt that it made no difference in how they accessed their GP practice, as they were refused accommodations and reasonable adjustments. Providing reasonable adjustments is a legal requirement for NHS and social care services, so they can ensure people who have additional needs can have equal access to healthcare.

"I don't feel that [my children] are given any kind of priority care or offered any support, when it is critical because they are already disadvantaged. I feel like they get disadvantaged more, when it should be the other way round to prevent further harm."

"My son is, but they seem not to pay attention or take that into consideration during appointments, causing access barriers."

Some respondents found that they or the person they care for were not treated kindly or with any additional understanding, despite the fact that their GP practice knew they were autistic.

"They already know – but I rarely see the same person twice. I would prefer that I saw maybe 2-3 doctors who actually KNOW me well. The uncertainty of who I will get is horrible. There is 1 doctor I refuse to see and another one I try to avoid because she shouted at me once."

"Some doctors at the practice treat him like he is a nuisance and ignore me even when I share with them that he is autistic. I believe GP'S have no training regarding autistic children."

In contrast, some respondents felt that their needs should still be taken into account despite a lack of formal diagnosis, particularly in light of long diagnostic waiting lists.

"I have told them. But the whole lack of a formal diagnosis means they don't/won't document it because they won't acknowledge self-diagnosis."

"In the defence of GPs, not everyone has a diagnosis of autism, but that does not mean that some individuals have autistic tendencies and this also needs to be recognised."

23% of people felt their experience was improved as a result of their GP knowing they were autistic. For some, respondents this was because awareness of their autism meant that reasonable adjustments were able to be put in place, for example, priority appointments, a quiet space to wait, or be able to bring someone to support to appointments.

"My autistic daughter's GP is fantastic with her and will even alter an appointment so she is seen first in the GP's clinic/session so that my daughter isn't waiting around too long in a crowded waiting room."

"I always obtain an appointment."

"My mum and dad can make appointments for me and come with me for support."

Some respondents found that clinicians were more patient and understanding with them when they were aware of their autism, which often meant they had a far more positive experience when accessing their GP practice.

"I feel they treat me patiently."

"My doctor has known me when I born and my Mum before she died and so he always says hello and talks to me."

"They let me express how I feel about my body."

"It helps them to be clear when they speak and to understand that I am very literal. That I don't like being touched unless it's essential."

"Since I was diagnosed I've noticed some GPs have taken more time to listen to what I'm saying and not jump to conclusions."

Other respondents shared that because the GP practice was aware of their autism, they were able to see the same GP consistently, which improved the quality and continuity of their care.

"GP very aware I will only talk to him, no other doctors."

"It helps me to see the same GP when I need an appointment as a new person is difficult because of the Autism, and extra tiring because of the M.E. My mental health in particular is managed through the same GP as he has a psychiatric background."

"Once we get past the initial call to the surgery and speak to a GP, our son is given a prompt appointment with his named GP."

However, for some respondents the support or understanding they received was inconsistent and their experience tended to vary dependent on the reception staff they spoke to or the clinician they saw.

"Sometimes. On one occasion a doctor asked if I would prefer the lights off which I found respectful and understanding."

"Sometimes, depends on who you see and for what."

Nevertheless, **77%** of respondents said that they would like their GP practice to know that they are autistic so that they could be more accommodating of their needs. Those few who were not sure or would not like them to know did not give a reason for this.

"Yes it would help them understand I need quiet areas to wait and be more understanding of me."

"Yes, I think it would help both parties to keep the diagnosis in mind."

Making an appointment

Over half of respondents faced barriers when making an appointment with their GP practice. Whilst some of these challenges reflected the difficulties faced by the general public, including limited availability of appointments and long waiting times on the telephone, these factors have a significantly greater negative impact on autistic respondents, particularly given the challenges they often face with social interaction and communication.

Many commented that the process of making an appointment is highly stressful and often induces anxiety, which is only exacerbated when reception staff are impatient and/or lack understanding of their needs.

"I dread every time I have to contact my GP surgery. It is always a negative experience and always leaves me in tears, it's like a trauma response. It's just so HARD."

"I don't like using a phone and having to wait increases my anxiety and makes me reluctant to call."

"I would be too nervous/anxious to book one for myself."

"The whole prospect of going to the doctors terrifies me. Even the event of having to deal with a receptionist or be in a waiting room."

Reception staff

Given that receptionists are the first interaction people have when contacting the GP practice, they play a pivotal role in supporting people to get the help they need, particularly when making appointments. However, the majority of respondents (**51%**) said that reception staff were not understanding or accommodating to them. A few respondents shared that reception staff don't have a good enough understanding of autism and were therefore not sensitive to their needs.

"Not at all. Awful. Had awful experiences as they cannot understand that it is a social communication disorder."

"Not always. It very much depends individual to individual. Usually, they can be quite challenging and rarely accommodate the need for an in-person appointment… nearly always they insist on calling using the telephone; which I find really hard, as I rarely use the telephone."

Several respondents said that reception staff had been rude, unkind and unhelpful which led to them feeling distressed and dismissed, and feeling reluctant to contact the practice in the future.

"No not at all, they are in general rude and unhelpful."

"No, I am always distressed when speaking with Reception staff as I find they are impatient and rude, more often than not. It is the part I find most stressful when going to the doctors."

"They are rude, and won't explain things I don't understand."

Other respondents noted that reception staff did not seem to read patient records, so were not aware of their autism and therefore did not accommodate their needs appropriately or think to offer reasonable adjustments. Many respondents found it incredibly difficult to get to the stage of interacting with reception staff, and that challenging reception staff was then another obstacle to overcome in order to see a GP.

"They're not accommodating of the needs of neurotypicals, why would we be different?"

"Due to difficulties in accessing services in the NHS a lot of the time access to information is dependent on asking the rights questions which one might not know of. It would be helpful if information was readily shared rather than dependent on people asking the right questions in order to access help and support."

"Information to help patients with the process is not made available unless you ask, and even then staff are often impatient and intolerant of people not knowing what to do."

In contrast, **25%** of respondents felt that receptionist staff were understanding and accommodating of their needs as an autistic person. Several respondents shared that they found reception staff to be patient, kind and helpful, whether or not they are aware of the patient's autism.

"The reception staff do come across as caring and I've not had any problems with the reception staff. They aren't discriminating. I find that they are very understanding and efficient."

"They treat my daughter the same as other patients. They are always kind and professional."

"Yes, the receptionists are always super kind and helpful if I go in person."

Other respondents found that reception staff were able to support with providing them reasonable adjustments or trying to meet their needs in a personalised way.

"Yes, if I ask for help then they provide help."

"Some receptionists understand the need for a bookable appointment."

"They help my Mum to get quick appointments for me."

"Offering phone appointments between specific times."

"They make a reasonable adjustment."

"They provide rooms to wait and chat in."

"Autism is logged on the system and there seems to be a good understanding of individual needs. We have been able to book appointment for health check with a named doctor."

13% felt that this was only sometimes the case, or that it depended very much on the receptionist the spoke to and/or the mode of interaction.

"When talking face to face with them, yes, they seem very accommodating. But when on the phone, no not really."

"If I go in person yes, but not on the phone."

"Depends on the staff."

10% felt that reception staff would not necessarily know that they are autistic and have additional needs, while others said they do not have much interaction or contact with receptionists, either because they do not access their GP practice very often or because their parent, carer or support worker contacts the GP practice on their behalf.

"Unless I say anything it is unlikely they know…I don't seem to see regular staff at the desk so it's not like they know me. It is difficult to know if I trust them."

"Because autism is a hidden disability, I don't think they really know I have it to be honest, they just see me as a normal person walking in. Some of them can be nice but others tend to be grumpy."

"I don't think they know. I don't tell reception staff."

Contacting the practice

At **36%**, most respondents preferred to make a GP appointment online. Respondents commented that they often find making an appointment online much easier, and limited feelings of stress and anxiety for some.

"I hated the phone at 8am system! But I am glad to just fill in an online form now. If I do need to contact for other things then my husband/carer does this on my behalf for the most part."

"Yes, the nightmare of automated phone systems. However, I can book online which helps but still means waiting for a call at an unspecified time."

"I'm glad they have the online triage system now as I used to dread phoning in the mornings, waiting and the receptionists were always really busy and fast and I would get anxious and muddled."

However, booking an appointment online does not suit everyone. Some respondents emphasised that they find eConsult difficult to use, noting that there are too many questions to fill in and is complicated to complete.

"Online consult is a barrier - there are too many screens to click through."

"I don't use the eConsult form as I find this particularly hard – it tires me and makes me extremely anxious. I am allowed to ring for appointments instead. The staff there are very nice indeed."

"Long, repetitive questions on the online forms."

In comparison, a few respondents would prefer to make an appointment online but are only able to contact their GP practice by telephone. A few respondents suggested that if they could book an appointment online, then they might not need to ask their parent or carer for support.

"The barriers are the eConsult which I cannot access and is also an issue for my carer."

"My mum does it for me. I do not like to wait on the phone. If I could book online it would help."

"I can't talk on the phone and no appointments online so I have to get someone else to make them."

28% of respondents make an appointment on the phone. However, it is important to again emphasise that for many respondents this is the only way they can contact their GP practice and is not necessarily their preference.

"I would prefer online but it all needs to be done by phone."

"I'm not given a choice. Mostly it's via the phone."

"We are only able to make appointments over the phone."

This lack of choice is particularly problematic, given such a large proportion of respondents expressed just how distressing contacting by telephone is for them. Respondents shared that interacting and communicating with reception staff and waiting on hold can be incredibly challenging and causes stress and anxiety for many.

"I find phone calls stressful, I feel like I'm being shunted along with little regard for how I'm feeling, or if have I understood the information."

"If I have to phone to make an appointment, and it takes around 30 minutes on hold to get through. Often I am so anxious that I hang up before I get through. It's made worse when staff are rude to me if I ask questions."

"I hate having to call at 8:00am and sit on hold for 20 minutes and then be talked down by reception…I get very stressed…I hate using the phone period."

It is evident that for many respondents, the stress of having to call for an appointment means they are either reluctant or avoid accessing their GP practice entirely.

"To make an appointment you usually have to phone at certain times or go into the doctors which can be stressful. I struggle with phone calls and so often avoid making appointments."

"I find the incessant hold music triggering when I'm trying to ring for an appointment, to the point that I avoid it at costs, and often end up in A&E with much more serious health conditions which could have initially been dealt with at the GP had it of been easier to get an appointment."

"I am unable to phone them as I don't feel comfortable using the phone. There are never any appointments available online."

17% of respondents prefer to make an appointment by visiting their GP practice in-person. Of these respondents, many commented that they find this a much easier and quicker way of getting an appointment. Although, a few shared that having to disclose the reason for their appointment in public can make them feel very uncomfortable and takes away their privacy.

"We're lucky we can walk to our GP surgery, I often find that's the best way to do it, because it's hard to get through on the phone."

"If I make an appointment at reception, the staff want to loudly discuss why I need an appointment, in front of all the other people waiting."

19% said they make an appointment through other means. Of this group, the majority said that they ask their parent, carer or support worker to contact their GP practice on their behalf. For some, this is simply their preference, while for others this is because they find contacting their GP practice themselves too challenging and inaccessible.

"I have to phone up for an appointment and that can be incredibly challenging, I often have to get my mum to do it for me."

"My Mum does it, I can't stand the hold music and can't get what I need online."

"I can't use the telephone system, so someone has to ring on my behalf."

"I can't talk on the phone and no appointments online so I have to get someone else to make them. It's always hard to get an appointment with the doctor I know."

The above findings about different ways to make an appointment demonstrate the diversity of needs and preferences among autistic people. It is clear that above all, there needs to be a choice in how autistic patients are able to contact their surgery.

Visiting the practice

39% of respondents stated that they faced barriers when visiting their GP for an appointment.

"Overall, I find visiting the doctors a hugely stressful experience. From booking the appointment to picking up a prescription I find the whole process overwhelming and feel that information to help patients with the process is not made available unless you ask, and even then staff are often impatient and intolerant of people not knowing what to do. Whilst I appreciate that a doctors is a busy place, I do not feel that patients are made comfortable in the environment and this is even more true for autistic people. I dread visiting the doctors as I feel that every interaction is pressured and rushed and that I am just causing a problem. I never seem to have a consistent GP who I see regularly and so I have to re-explain everything each time I go to the doctors."

Waiting rooms and times

One of the most significant barriers faced by the majority of respondents was the anxiety and stress around waiting rooms. Respondents described waiting rooms and the environment of GP practices as too loud, public, and busy and often causing a sensory overload a result. For many autistic people, the build up to the appointment can be so stressful and anxiety-inducing that when it is time for the appointment, they feel unable to express themselves sufficiently or take in any information given.

"Waiting room. Do not cope with waiting but public waiting room is a huge barrier."

"The waiting room is a really difficult sensory environment for me. "

"I have to wait in an open room and I get anxious round strangers."

"I get so anxious in the waiting room that I often can't fully articulate my needs when I see the GP."

"There is no quiet space to wait and I can't use headphones to block out the sound as then I won't hear the alert to call me to the room."

Likewise waiting to be seen by a clinician was mentioned as a barrier by some respondents. They shared that delays and long waiting times made an already challenging situation even more difficult and only added to their discomfort and distress.

"I get anxious going in there, and waiting makes me more and more anxious."

"Waiting due to GP running late. I get anxious."

Staff attitudes

The second most significant barrier mentioned was the attitude of clinicians, with respondents noting that clinicians are not understanding, patient, or accommodating. Many have had a negative experience during their appointments, in which they felt rushed, judged, misunderstood or dismissed. A few commented that clinicians treat them "like a child" or as if they "do not understand" and felt clinicians do not take the time to listen to them or their needs.

"Impatient, not understanding of going non-verbal, not listening, refusing referrals."

"Fear, judgement, not believing me, treating me as difficult and making it obvious that they don't want to deal with me."

"I never see the same doctor and not all of them understand my disabilities and they treat me like a child once they realise I'm disabled."

"My GP won't read the symptoms etc I write down and always seems rushed. I feel I'm treated like I don't understand and it is assumed I don't take care of my help or know the information to choose to."

"In the past I have felt judged by the GP."

Similarly, respondents shared that clinicians do not seem to have an adequate understanding

of autism, and will often speak to their carer, parent or support rather than directly to them, which many find disrespectful.

"Autism is completely ignored."

"GP don't have much understanding of autism…GP rely a lot on the staff who are supporting…GP rely so much on home staff, there is no interaction from GP to the individuals."

It is then unsurprising that most respondents did not feel very understood by their GP:

14% felt very understood by their GP

18% felt mostly understood by their GP

26% didn't feel very understood by their GP

22% felt not at all understood by their GP

20% weren't sure

Likewise, some parent and carer participants voiced concerns that their GP seemed to have very little knowledge of autism at all. This can cause issues and barriers to support outside of healthcare too:

"The GPs know next to NOTHING about Autistic people. And even when we need referrals from them for specialist intervention, they are unable to help. I had to personally "teach and educate" my GP in order to help my child. Many a time Local Authorities request information from GP before help is given, but that is next to impossible if the GP does not even recognise the need of my child."

Communication barriers

Communication was another barrier raised by respondents, with some emphasising that their communication needs were not understood or taken into account. Some respondents commented that the clinician did not understand that autistic people may become anxious and as a result non-verbal or have difficulties communicating their needs. Others said that clinicians tend use complicated language and terminology which they find difficult to understand. For autistic people, communication barriers can stop them from attending appointments, or mean that appointments are not as helpful as they could be.

"I feel overwhelming anxiety which can cause me to go non-verbal."

"Talking to me in speech I do not understand, not simplified language. Being cold towards me not friendly even when I explained communication disorder (autism, learning difficulties) they still treat me beyond my means, which makes me feel unwelcome. Hate seeing doctors, I will not go."

"Yes, I am extremely anxious and nervous and struggle to communicate my needs."

One respondent gave an example of when clinicians were not accommodating or flexible in their communication with her husband:

"The expression was 'how are you doing XXX', and he said 'how am I doing what?' he doesn't understand. They asked him 'why can't you answer the questions properly'"

Communication barriers between respondents and their GPs were particularly evident when considering pain and 'pain scales'. Several respondents felt that the clinician was not aware of the known difference in pain sensitivity and presentation for autistic people, in addition to the difficulty some autistic people face in describing feelings, sensations or pain[32]. Respondents felt that if clinicians were more aware of these factors, then they would be able to probe or find other way for the patient to communicate their symptoms effectively, rather than using the standardised pain scales.

"Understand that we experience pain differently, so we might look fine but if we are telling you that something hurts, even though we aren't screaming, we could still be in agony with something seriously wrong. We also don't necessarily know how to convey what's wrong and we may need some help describing or getting there e.g. does the pain feel like this or like that, can you point to what's wrong."

"It would helpful for the kids if the GP was aware of their presentation. Because I think obviously autism is such a wide spectrum, you know you've got children who are hypersensitive, and then you've got children who just don't respond, and it's helpful for the adult to know where that child is on the spectrum. My son had a broken wrist and it took him two days to tell me his arm was hurting. That's something that medical practitioners need to know. My kids would never say anything higher than 2 out of 10 on a pain scale. I think a purple folder could be useful, but I don't think the GP would actually even acknowledge it, so I haven't bothered. The message still hasn't got across that every autistic person is different, and they present in a different way, with different needs."

[32] Increased pain sensitivity and pain-related anxiety in individuals with autism - PMC (nih.gov)

Lastly, a few respondents mentioned that their GP practice is not physically accessible and/or has poor signage, meaning respondents do not know what to do, where to go, or where to sit, which they can find very stressful.

"Not always sure where I should wait."

"The parking is often an issue, even with my blue badge. The accessible door to the practice is rarely working and I struggle with my crutch to open it. I find standing in line very difficult and painful and have to sit down."

"Booking in. Anxiety about where to sit etc."

13% of respondents said that they only sometimes faced barriers, and often this was because their parent/carer/support staff with them mitigated these barriers, although they mentioned they would struggle to access and visit their GP practice without this support.

"I take my mum as I can't take in a lot of information - I would prefer them to write it down."

"I would struggle without my carer (mother)."

"It is OK if my mother can come. She can speak to the receptionist and the doctor."

Some respondents said they find it too difficult to visit their GP practice and/or have had previous poor experiences which have made them hesitant or reluctant to revisit. Not being able or comfortable to use GP services means that autistic people are at a higher risk of not receiving the right healthcare at the right time.

"Yes, I have Chronic Fatigue Syndrome too, so am too exhausted, and sensory overloaded. I rarely see GP and don't like the appointments so avoid it whenever I can. I haven't seen GP in a very long time. My Mum does my health needs."

"I never visit my GP, they only offer phone appointments."

"He should really get a medication review because he takes a lot of medication but we don't engage with services, we haven't engaged with the GP for a long time. If he had to, I would go with him, but he's had such bad experiences we don't go."

"I avoid going to the doctor because I am anxious and scared of being prodded or poked or sent for more appointments."

Positively, **40%** of respondents said that they didn't face any particular barriers when visiting the GP. Sometimes this was because the staff members were particularly friendly and helpful, and had a good understanding of their needs and/or autism.

"My experience with my son visiting the GP surgery has always been very positive. "

"They're brilliant."

"Staff are always friendly and helpful."

"My GP Practice is fantastic and patient and supportive in general. So I am very lucky."

Others found that the environment was manageable, and information was clear which was helpful.

"They are very well sign posted, and the waiting room is usually quiet unless there are children there."

"No because it's quiet."

However as mentioned above, some respondents did not report facing challenges in accessing their GP practice because they were able to have a parent, carer or other support with them to help mitigate the barriers.

"I take my mum as I can't take in a lot of information - I would prefer them to write it down."

"I always have staff with me. I would ask the receptionist if I went on my own."

Some of these barriers are similar to those that the general population face, due to well-documented pressures on GP services[33]. However, it is very clear from this research that these barriers have such a significantly detrimental impact on autistic people's access to, and experience of GP Services and contribute to their poorer health outcomes.

Mental health and wellbeing

As has been made clear in previous research, autistic people are more likely to experience mental health problems, but often face difficulties in receiving support for them in a timely and appropriate manner. Autistic people can be particularly vulnerable to anxiety and depression

[33] Pressures in general practice | The King's Fund (kingsfund.org.uk)

but might have difficulty in identifying or expressing their feelings[34]. If GPs and other clinicians are not alert to this, it can mean that diagnoses and support is missed or delayed.

Just **32%** respondents said that their GP had discussed their mental health with them.

"Yes, in one appointment."

"Yes, medication was prescribed."

"Yes, [mental health] is the primary topic of our conversations."

Although mental health and wellbeing had been discussed for some respondents, they did not always find that this was helpful. Often, this was because the clinician's lack of awareness and understanding of autism meant that the support they offered with mental health problems was not appropriate to the respondent.

"Briefly discussed. With assumptions and no understanding of impact of neurodivergent conditions on mental health and employment."

"They have not done anything to help me."

"We saw the mental health practitioner at the surgery. She was not the best, to be fair I don't think she had much understanding of autism. She was just saying things like 'try not to think about these things' and I was thinking well you don't really get it, he can't help his obsessions, and that's often the way with people with autism."

Similarly, one respondent shared their frustration that each symptom, problem or diagnosis was considered in isolation, and their healthcare was not holistic enough.

"This is something that is overlooked and not managed. Everything is in isolation which causes issues."

Lastly, some respondents shared the feeling that their mental health was overlooked or dismissed, even when they were clearly expressing a need for support.

"I told them I am not well in my mind, and they told me I can go online to read things."

"I have been on Citalopram for over 20 years but no discussions about my mental health or wellbeing since."

[34] Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf

"When I was suicidal, all I had was a phone call for less than 5 minutes."

A few respondents did have a positive experience when speaking with primary care clinicians about mental health and wellbeing. This parent found her son's GP to be particularly kind and patient, treating him as a 'proper individual'.

"When we have seen the GP recently it's been for a couple of mental health issues and the GP was really really good with him. I was so impressed that I emailed the surgery to say how lovely she'd been with him. I was just impressed that she treated him as a proper individual, you know, talked to him, rather than sort of, going via me. She was really kind with him, he asked a lot of questions and it didn't faze her."

However, many respondents also stated that they or their parent/carer often initiated the discussion about their mental health and wellbeing, rather than being prompted by the GP to talk about this.

"Only when prompted by my parent."

"Yes, but only when I have asked for it. I have had experiences at another surgery where my mental health issues were not supported at all."

"Mental health and well-being is only discussed if I choose to bring it up during my appointment. I never seem to have a consistent GP who I see regularly and so I have to re-explain everything each time I go to the doctors."

"Not unless I have come with an issue around it."

"I discuss it with my GP. They do not pro-actively prompt."

This patient-led approach could mean that the mental health needs of autistic people who struggle to identify and communicate their emotions and feelings are missed, because the topic has not been directly addressed with them or their carer. Given the poor mental health outcomes and suicide rates for autistic people, early identification and intervention is really important. This respondent shared the barriers faced that make it difficult for the person they care for to communicate their mental wellbeing.

"When the GP says to him 'how do you feel?', it takes him time to formulate how he feels, and he may not know, and there's never that time in a consultation to get that across."

Concerningly, **43%** of respondents had never spoken to their GP about their mental health, despite many clearly expressing a desire or need for this. Some respondents had faced resistance from practitioners about discussing their health – whether that be physical and/or mental.

> *"They will barely discuss my physical health. I was told that I cannot book an appointment for an ongoing or chronic condition, and that I should go to A&E if I require even routine care, as appointments are only for new and chronic conditions. "*

> *"No just the bare minimum of ticking boxes over yearly disability checkup. I am seeing a psychiatrist for my anxiety. When I've tried to talk to the doctors about it you get nothing no understanding whatsoever it's like they don't want to see me or help."*

Other respondents felt that they had been dismissed or misunderstood by clinicians, despite reaching out for help.

> *"No. Although during a recent visit to discuss about issues with menopause was given anti-anxiety and depressants instead."*

> *"I have been misdiagnosed for years when reaching out for help."*

One parent felt that if her son had a consistent GP who understood autism, they would have been more likely to pick up on any mental health needs.

> *"No! They have never discussed it. They could if they "realised" or know and understand [my child] is Autistic. However, they do not. Plus, he is seen by different doctors. So… "*

Reasonable adjustments

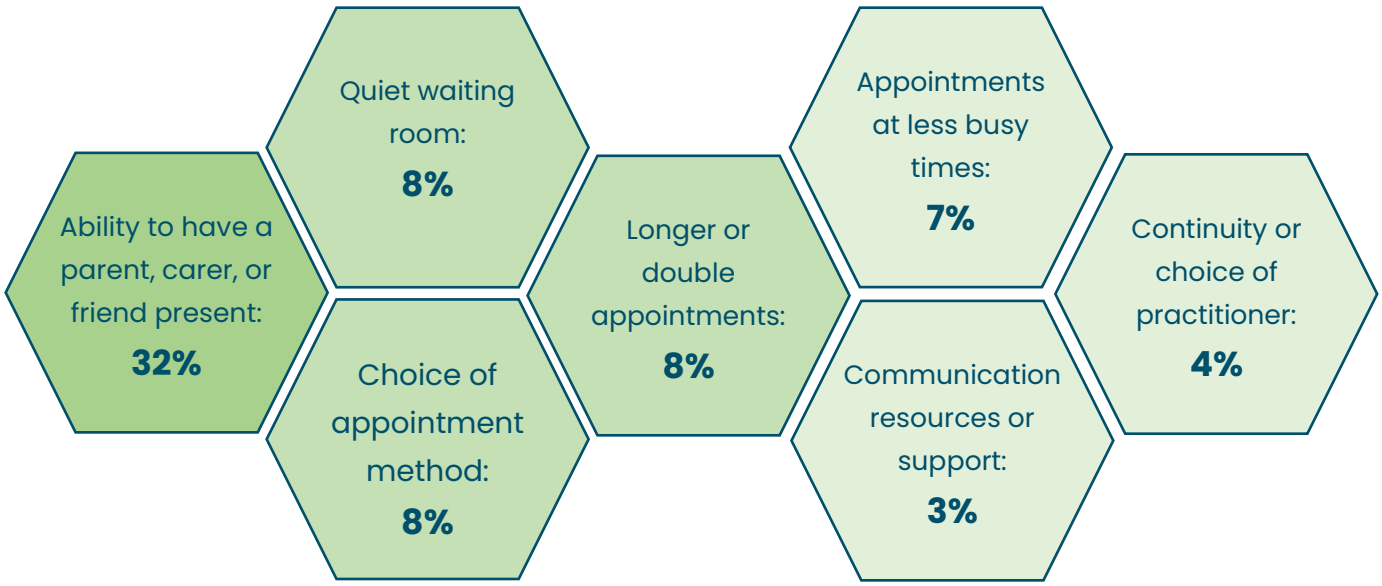
Awareness

Under the Equality Act (2010) GP practices must ensure that services are accessible by implementing reasonable adjustments to ensure everyone has equal access to health services[35].

42% of survey respondents were aware that GP practices were required to offer them reasonable adjustments as an autistic person. **45%** said that they were not aware of the requirement for reasonable adjustments to be made, and **13%** unsure.

Awareness of each reasonable adjustment was very low, at **under 10%** for all except for the ability to have another person present at appointments:

[35] Reasonable adjustments for people with a learning disability - GOV.UK (www.gov.uk)



Concerningly, **66%** of respondents were not aware of **any** of the above adjustments listed in the survey, and did not realise that it is their right to receive accommodations to ensure their access to healthcare is equal.

"I'm shocked after reading this!"

"I know nothing about these."

"Are all of these available to me??"

Furthermore, **70%** of respondents had never been offered any of the above reasonable adjustments, and **14%** were not sure or could not remember if they had been. Worryingly, a few respondents commented that they have asked for reasonable adjustments but were refused.

"I have asked for several of the above but been refused on several occasions."

"I've asked but have been met with confusion and resistance."

"They don't do this as far as I know."

"None of these are provided or offered."

For the **15%** who had been offered reasonable adjustments, it was mostly that they were allowed to have a parent, carer or support worker come into their appointments. A few mentioned that they had been given a longer appointment, were able to see their named GP,

were able to request a particular type of appointment, and had access to a quieter waiting room.

"I have asked for telephone appointments, longer appointments, named GP."

"Time was changed so that my daughter had less waiting time in the waiting room for her appointment."

"They ask if I need my dad with me."

However, several respondents had to explain their situation and advocate for themselves or their child every time.

"My mum has asked for a longer appointment when I needed a lot of vaccinations done - it took a month to get approval. My mum had to do this as there was no way I could do this at all. We didn't know they had to do this, it was just what she rang and asked for but was told no, so she had to push for it."

"We have to ask and explain our son's disabilities and special needs, every time we call."

"I complained and made them adjust in some level and accept telephone appointment and accept my mum contacting my GP."

Some respondents also mentioned that although their own GP was accommodating, there was variation between staff members and the support they offer.

"Every person I've spoken to is different. Some nurses and doctors are very understanding. Others don't seem to understand or care very much."

"Doctors who have known me since I was a baby are more understanding and accommodating."

"Dr XXX is great. He is calm and get it. No one else is like this."

Waiting rooms and waiting

When asked what reasonable adjustments would improve their experience of visiting the GP, **most** respondents said that they would benefit from a quiet, calm waiting room and/or the ability to book an appointment when the GP practice is less busy to help manage and reduce their anxiety and the risk of sensory overload.

"Quiet/dark waiting room."

"Quiet waiting room. Appointments at less busy times."

"Appointments at less busy times e.g. at the end of the day."

"separate room to wait, quiet times for appointments."

Linked to this, respondents said they would like waiting times to be shorter and/or to be kept updated regarding their appointment time, emphasising that this would help them to manage their anxiety.

"My daughter who is autistic finds it difficult to wait so less waiting times."

"Being kept more up-to-date with my own waiting time."

"To know rough waiting time so I could go in later if there's a long wait."

Other reasonable adjustments

The next **three** top adjustments that autistic respondents would benefit from are:

1. The opportunity to have a longer or double appointment, so that they do not feel rushed and can have enough time to communicate their needs. Respondents also commented that having a longer appointment would enable them to discuss multiple concerns at once, saving them from having to book another appointment.

"Covering as much as possible in as few appointments as possible, because I find it really stressful."

"Allowing more than one issue to be discussed in an appointment. These are often related. Whilst I understand time pressures there is little attention for holistic care."

"Extended appointments would make a huge difference. I get so distressed about trying to fit in everything I need to say, that I end up not able to say anything of importance at all. Then I feel rushed and come out feeling worse than when I went in."

"I find normal, short appointments very hard to cope with. I am given double appointments generally, but if I need a quick appointment for a particular problem I get a random GP and under 10 minutes with them. I need a double appointment for this too, ideally. The short appointment makes me very anxious, and because I haven't taken everything in during the appointment, and haven't asked all the questions I have (about a medication I will have to take, how the illness will develop and get better etc.) I often have to recontact the surgery and speak to them more than once in order to get all the detail I require. (I really require detail!!) I end up taking up more of their time overall because they rush me to begin with."

2

A consistent, familiar GP for all their appointments who knows the patient. This continuity of care is important to autistic people and enables them to build communication, trust and rapport. It also means that they do not need to keep repeating their needs and/or medical history.

"Continuity of care would make a huge difference. It's really hard when you see a strange face every time."

"Seeing the same doctor, not needing to speak to other people."

"To be able to choose a Dr to see and to see the same person."

"Only being offered to see certain doctors as not all are friendly or explain themselves very well, that leaves me stressed or upset."

One respondent has a particular good relationship with her children's GP and shared how much of a positive difference it makes both emotionally and clinically.

"It can be difficult having to wait for the child to be seen by the same GP – that's a big issue, it has to be the same GP, but often there's no availability, you have to wait a month or more. Our own GP is very sensitive and very caring and very knowledgeable, it comes across as highly sincere and she's keen to refer us to any services whatsoever that we ask for. It means an awful lot, it means a huge amount.

She is highly understanding of the condition and other related conditions, and it's really helpful. She is very understanding when anything related is pointed out, because she's made herself knowledgeable. The major positive is that she went away and took the time to look into the condition, she took time out to understand it -I thought that was very nice of her. But that's just one GP, and the rest of them don't know that much. That's why I find it best to see her."

3

Although it does not typically fall under reasonable adjustments specifically, it was very clear from most respondents that more understanding, patience, sensitivity and respect from clinicians was really important and would make a huge difference to them. Many respondents felt that these were often absent and made them feel like uncomfortable, misunderstood and as if they are a burden.

"Extra time, patience and sensitivity towards me."

"Extra care in how they talk to me and treat me."

"It would help me if they did not treat me as a pet animal."

"Most importantly someone that doesn't treat you as freak of nature and burden."

"Treating us with respect. Doctors talk to me in technical terms and even though my carer is saying he has a communication disorder and deciphering what they're saying, they still don't make an effort. It feels like they just don't care you're made to feel uncomfortable."

"Just try to understand us and be kind. We are all different. Going out does not fix things with autism."

"Better training for staff. There is a lack of understanding for severe learning difficulties and people that cannot communicate or understand."

This included respondents wanting reception staff to be more understanding and aware of the needs of autistic people and the reasonable adjustments they can be offered.

"Better informed reception staff with an understanding of how autism affects people."

"Reception staff being aware that I'm autistic and being less aggressive (although I understand their job is stressful.)"

"For each receptionist to be aware of the reasonable adjustments required rather than having to ask all the time."

Respondents made lots of other suggestions which they felt would help them and other autistic people to use and access their GP practice. This included the ability to choose the type of appointment, whether this be face-to-face, online or by telephone to accommodate their individual communication needs and/or preferences.

"Being able to request in person appointments rather than not having a choice and only being offered phone appointments."

"Getting an in-person appointment, not a telephone call to my mum."

"The eConsult system and submitting photos does not work for autistic people or anyone with a social communication disorder, it needs to be face to face."

Similarly, when offered a telephone appointment, respondents would prefer if an exact time could be given rather than a large time window. Not having an exact time can increase anxiety and prevent autistic people from being able to sufficiently communicate their needs and in some cases, lead them to avoiding the telephone call entirely.

"If I get a phone appointment, I need to know who I will be speaking to and when they will call, but reception won't tell me this, and will only tell me 'between 9 and 2' for a phone call. This makes me so anxious that I can't usually articulate my needs to the GP."

"Not always knowing when they will contact me can lead me to avoid it completely."

Respondents also mentioned that they would like clinicians to communicate in a way that is accessible to them, including speaking more slowly, using different words and using alternative ways of interacting. Others suggested that receiving written information before and after the appointment would help them to manage their anxiety and enable them to feel reassured and prepared.

"I have trouble talking about my body, so a different way to communicate."

"Written information telling me what I should do after seeing them about something."

"Understanding of my needs and that language used is very important."

Respondents felt that better signage in GP practices would improve their experience of accessing their GP practice, and would help them to navigate an environment which might feel uncomfortable and distressing.

"Extra information would be extremely useful as I get anxious when I feel I don't have all the information I need. Information to show if appointments are running late would be useful to reduce stress and clear signage to point me to where I would need to go would help to reduce anxiety."

"Extra signage would be useful, last time I thought the automatic door work and I have waited outside for it to work until someone came and pushed it."

"Better signage, I got used to the names of the waiting rooms, then they changed them to colours, but I cannot remember where to go now and this is stressful."

Lastly, respondents would like to be able to bring someone to support them at their appointments, as some noted this request has been denied. They would also like to be able to easily nominate someone to act on their behalf in making appointments, but also in receiving test results and other types of information.

"Ability to have a friend present (I usually have to take someone but sometimes this isn't allowed).

"Easy way to nominate someone to act on my behalf making appointments or getting results/information."

It is worth noting that a few respondents could not think of any reasonable adjustments or personalised care they would like to be put in place, largely because their GP practice is already very supportive and accommodating.

"I can't think of any. My GP practice is fantastic and patient and supportive in general. So I am very lucky."

"I think my practice does very well in accommodating me."

Autism health check

Pilots are currently taking place in the NHS to implement Autism Health Checks with the GP which are specifically for autistic people in order to identify any health needs earlier, and to improve their overall health.

69% of respondents said that they would find a health check specific to autistic people helpful. Just **9%** would not find a health check helpful, and **23%** weren't sure if they would.

"Basically time to discuss all aspects of health care, so we can bring up minor issues but as part of a holistic check as I really struggle with making appointments for one issue when often many issues overlap."

"An Autistic child may not be able to tell you their needs even if they are verbal. Routine check-ups can help diagnose any anomalies and issues with them."

"If nothing else, it would mean they're not slipping out of the system otherwise, because it is quite easy to do so. They just need that little extra help to make sure that somebody's looking out for them, otherwise it would be quite easy for them to get missed, or maybe not go to the GP at all, because it's that first step of making communication"

For those who would like an Autism Health Check, the majority would like a holistic approach to their health to be taken, and for this to include:

- A basic health examination (blood pressure, height and weight)
- Review of medication
- Dietary information and weight management support
- Mental health and emotional wellbeing
- Signposting information, including social and wellbeing support such as employment, education and housing
- Information on how to check for signs of cancer
- Blood tests
- Conditions typically more common in autistic people

"Definitely help with diet. My diet is absolutely awful and that's because of all the sensory taste and texture difficulties I have with my autism. Weight management support would be useful. Checks to do with my heart rate and blood pressure too. Physical exam, or instructions on how to check for physical changes. Like breast checks and examinations. There are lots of things I should be doing for myself now I am an adult but I am not sure what."

"Physical health. I'm never really sure if my body is working well."

"Weight check (as long as the individual is comfortable with that), making sure the person is keeping up with their dental/eye check-ups, asking if there are any other concerns, potential sign posting, blood tests."

"Mental health, wellbeing, being offered any support that is available as its hard to find on my own, time to raise any concerns I might have."

"Just general physical wellbeing check, and mental health review."

"Standard tests such as height, weight, blood pressure and question about any health worries,

"Co-occurring conditions, diet, mental health, signposting to other things in the community, checking any other health problems."

"Medical risk factors associated with Autistic people."

Respondents also felt that having a regular review of health would enable them to build a relationship with a GP.

> *"An opportunity to build a relationship with the GP as wanted to build trust which is very difficult nowadays."*

These suggestions from autistic people about what they would like to be included in an autism health check show that having a GP who knows them and understands autism would make a significant difference to their wellbeing. Furthermore, having the opportunity to see their GP every year for an extended appointment would mean that autistic people feel more confident visiting their GP at other times, and would be supported in a holistic way that takes into account their individuality and specific needs.

"Autistic children are always left behind"

Sam is the mother of a 13-year-old autistic boy who shared her experience of GP services for her son. She has had to constantly advocate for her child to receive the care that he needs.

"The support is nothing, zero. They don't recognise him as having autism, so…"

"A GP Surgery should be safe space for an autistic person. They should be more friendly, more accommodating, more open, more welcoming so that parents can find it easy to communicate the needs of their children and not feel like they are being a bother and that GPs are doing them a favour."

She shared multiple poor experiences with GP services:

"I've had a doctor tell me… for example, he wasn't sitting still and they said, 'can you tell him to sit still?', and I said, 'but he's autistic…', they said, 'yeah, but tell him to sit still'. And I said, 'it's not him' - I have tears in my eyes as I'm saying this - I said 'he's not doing it deliberately, it's just who he is', and they just ignored me and carried on. As mothers, there's nothing you can do, you cry and pick yourself up and carry on."

On the barriers to receiving reasonable adjustments, Sam said:

"You can only ask for these things if there's that room to manoeuvre, that safe space for you to say something, to feel free to request such services. But when you feel like you're getting on their nerves, you're made to feel uncomfortable. Because of that, I don't even take him to the surgery unless it it's really really really needed."

Sam shared that GP staff need more training on autism:

"I feel strongly that the GPs need to be educated. They need to be trained. I feel that they are not trained, I've been to a few who are nice, there was one who was accommodating, but even him, I went back to him for a referral to CAMHS, and he didn't know what to do. He didn't know what to write in the referral. No clue what to do. So I realised that they are not trained, so they don't know how to handle our children with autism, they don't know. I was expecting that it would be in his notes, but they don't know. They need to be trained to understand that everyone is different. They don't know, and they don't care to know, like 'it's none of our business'. They don't take the time to know *these* children, or patients, adults, they don't take the time to know them in a holistic way."

"It should be a requirement for them to know these patients. Not just the GPs, the receptionists should know too, because they are the first port of call. They've been given so much power to decide what to do, so they should also know the patients and their requirements."

She felt that an autism health check would be very beneficial:

"Parents up and down the country like me say why bother, they don't even want to take care of you anyway, they won't listen to you. If we had a routine check every year, you'd know that someone cares enough to listen, to do something about it. The way it is now, no-one cares enough to listen. you just resign yourself to the situation and you conserve your energy to look after [your child], instead of going and being slapped in the face every time with 'no, no, no, no, no'. So if there was something like an autism health check put in place, that would be amazing. They should know that they can call their GP and get help."

"The strength that you have is to look after your child, not to be fighting [the doctors]. They are not taking who he is into consideration, to meet his needs. It shows that they

Support and improvements

63% of respondents said their surgery wasn't doing anything to support autistic people, or they didn't know what they were doing to support them.

"Not heard of any support really, I asked for an OT assessment and was rejected, for mental health support, was rejected, however they did refer me to Mind, an organisation that offered me discounted Talking Therapy sessions."

"I'm not sure it really is. One doctor offered to turn the lights off as they were painful for me. I haven't seen any other direct help."

"I do not feel anything has been put in place to support autistic people and, if there is, it has not been made readily available to patients."

However, some respondents shared some positive experiences, including examples of particularly caring and understanding staff members, and accommodations such as faster appointments or separate waiting rooms.

"My doctor is understanding and is patient when I get stuck on words or find it difficult to speak."

"They are generally very supportive."

"Our GP practice is super at looking after my daughter's autistic needs. I do think this is more driven by her actual GP rather than the practice itself though."

Many respondents' experiences were often dependent on being able to speak to the right person or GP, rather than being able to rely on the whole system to meet their needs.

"There are individuals who are patient and try to accommodate you within I'll fitting systems and processes... but this is fairly rare."

"Once I can speak to my son's named GP everything goes very well."

Suggestions for better care

When asked how GP practices could better support autistic people, the top three improvements suggested were:

1. Clinicians and reception staff to receive training and education about autism and the needs of autistic people, so that their understanding, awareness and the care they give is improved.

"Training their staff to understand the challenges autism presents in situations like these."

"They should all be trained to know, acknowledge and understand autism."

"Be better educated about autism, from reception and including GPs."

"A little bit more understanding and read and educate themselves on autism."

2. Receptionists and clinicians to treat autistic people with more kindness, respect and empathy, and be willing and proactive in accommodating for their individual needs.

"I think some extra consideration of the idea that 'not all disabilities are visible' would go a long way, not just for autistic people but for others too."

"To not be discriminating and take their needs seriously. The support they need is paramount and prevents harm. It's not optional, the support that they need is critical to help them thrive and live their best lives without further impairment. It's sad that's it's not more important within modern day society. It should be. They deserve to live full lives like everybody else, but they can only do that with the correct support. It should not be put on hold like it's unimportant, because it's detrimental."

"As long as an ASD person is treated as an individual with their presenting challenges being recognised and supported, they are listened to and then signposted to services available in the community for ASD people, then things should go well."

"If they treated me as a human being."

3 GP practices to offer and accommodate for reasonable adjustments, including being able to bring someone to support, choice in the type of appointment given, choice in clinician, a longer appointment, and having a quiet area to wait in.

"Having a quiet room, so they can feel calm before seeing the doctor."

"Be aware of the special needs/reasonable adjustments up front."

"Allow me to nominate my parents to act for me."

"An extended appointment time."

"Somewhere quiet to wait would be super, if we could wait in the car… if I went in and registered to say we're here, and then sit in the car and wait, and then get a quick call to say it's your turn to come in, that would be great, it reduces anxiety."

Some respondents suggested that patient records should clearly state if someone has autism. They felt that having this information immediately flagged would help reasonable adjustments be put in place and offered, and also prevent autistic people from having to keep repeating their diagnosis and medical history.

"Read, recognise and know their patients' history and notes."

"Flag up on top of the file that someone is autistic. So everyone you see knows you have a disability…I should not have to keep saying every time I ring up that I am special needs…you should be letting me know what you know and what you can do to help me but instead I have to keep telling people this so that you would understand and be kinder."

"Acknowledge who they have on their records with autism."

Having multiple ways to book an appointment was also important to respondents, with many commenting that they would like the option to contact their GP practice online rather than having to rely on the telephone, particularly as this interaction can be very distressing for autistic people.

"Having ways to make appointments without using the phone."

"Offering a range of ways to book and attending appointments."

"Make it easier to communicate with them online or via email and make it easier to book appointments online."

Autism Health Checks were also important, with respondents commenting that having a regular review of their health with a clinician they can build a rapport with would be useful and encourage them to access health and care services.

"Regular reviews would be welcome."

"Regular checks even when healthy to allow trust so when health issues arise anxiety is lower and support can be accessed."

Summary

There is such a variety of needs and experiences within the autistic community, and this project has really focused on understanding and highlighting the breadth and depth of people's experiences. Autistic people's voices are seldom heard in such detail, and the stories shared in this research emphasis and communicate the lived experience of autistic people in a tangible way.

A core theme to recognise from this work is the extent to which the problems that many people face when accessing their GP practice are completely debilitating, scary and anxiety-inducing for many autistic people. Several respondents shared that the entire process of accessing and visiting their GP practice was so difficult and caused such distress that they avoided it completely, which puts their health at risk. Common reasons for this were due to difficulties communicating, unmanageable waiting times and environments, and feeling dismissed or rushed by staff. Positively though, some respondents shared experiences where individual GPs or other staff members had made an effort to be supportive and extra-patient, and these seemingly small acts made a big difference to their comfort and experience.

The positive experiences some autistic people had were most often the result of front-line staff taking the individual initiative to meet the needs of their patients. Their actions do not appear to be well enough supported or encouraged by the network within which they operate and the impetus cannot solely be on clinicians (and autistic people and their parent/carers) to stretch and shape the system in order for autistic people to receive basic primary healthcare.

The findings have also shown the importance of putting a clear emphasis on understanding how individualised autism is. Each autistic person deserves to be asked what their specific needs are, and for those needs to be met. For example, many respondents could not use a telephone, but preferred to make an appointment online. Conversely, others would benefit from being able to make an appointment over the phone instead of using the online system. Offering reasonable adjustments requires GP practices and staff to adapt to the needs of the patient concerned, rather than providing a cover-all approach. It would also help autistic people and their parents or carers to feel confident in requesting for their needs to be met.

The findings of this research highlight the inflexibility present in some areas of GP practices – when the workings of the system are prioritised above the individual needs of its patients, it's often the most vulnerable groups who fall through the net or aren't adequately supported. Whilst this inflexibility is a frustration for many patients, for autistic people, it has an extreme and directly detrimental effect on their lives and their health. For some autistic people, these barriers mean that they don't receive any healthcare until it's urgent, and their quality and length of life are reduced as a result.

Recommendations

It is well understood that General Practice is facing significant pressure due to a combination of system factors, patient factors and supply-side issues[36]. However, it is particularly important that people who are already at a disadvantage, such as autistic people, do not suffer more as a consequence of these pressures on services. As such, based on the findings of this research, we advise Hertfordshire and West Essex ICB Primary Care Board to implement the following recommendations:

Identification

- Support the implementation and promotion of the 'digital flag' for autistic people to add to patient records that indicate their eligibility for reasonable adjustments and enable the GP to be aware of the diagnosis.
- Reception staff should be proactive in reading patient records and checking whether any additional support is needed.

Reasonable adjustments

- Ensure that all GP Practices are proactive in offering reasonable adjustments and are making patients aware of their right to ask for them. Any support requested must be implemented and not denied.

    - Of particular importance are:

        - Longer or double appointments
        - Appointments at less busy times
        - A quiet or private place to wait
        - Ability to see their named GP
        - Ability to choose the type of appointment they have
        - Ability to bring someone to support them at their appointment

Communication

- As stated under the Accessible Information Standards (2016) clinicians should ensure they are communicating with autistic people in a way that is accessible to them, and providing information in a range of formats.

[36] Pressures in general practice | The King's Fund (kingsfund.org.uk)

Flexibility of Appointments

- Improve flexibility in the methods available to make an appointment to take into account individual needs and preferences – there should always be more than one way to book an appointment.

Training and awareness

- Ensure the provision of autism and neurodivergence awareness training for all clinical and non-clinical staff working in GP practices.
- Clinical staff should take a holistic approach when interacting with patients, examining both their physical health as well as their emotional wellbeing.
- Clinical and non-clinical staff should treat autistic people with respect, dignity and understanding, and play a proactive part in supporting autistic people to communicate their needs and concerns.

Autism Health Checks

- Continue to pilot Autism Health Checks across GP practices in Hertfordshire, and find out from autistic people what works well, what could be better, and what checks should be included.

Appendices

Respondents were patients at the following GP Surgeries:

District	GP Practice	Respondents
Broxbourne	Park Lane Surgery	2
	Valley View Surgery	1
Dacorum	Rothschild Surgery	2
	Highfield Surgery	1
	Lincoln House Surgery	1
	Everest House Surgery	4
	Parkwood Drive Surgery	1
East Herts	New River Health	3
	Marymead & Knebworth Surgery	2
	Hanscombe House Surgery	1
	South Street Surgery	1
	Wallace House Surgery	2
	Dolphin House Surgery	1
	Church Street Surgery	1
	Helix Medical Centre	2
	Puckeridge & Standon Surgery	1
Hertsmere	Manor View Practice	6
	Attenborough Surgery	2
	Grove Medical Centre	1
	Schopwick Surgery	1
	Fairbrook Medical Centre	1
North Herts	Birchwood Surgery	2
	Sollershott Surgery	1
	Nevells Road Surgery	2
	Bancroft Medical Centre	1
	Regal Chambers Surgery	3
	Portmill Surgery	1
	Baldock Surgery	4
	Whitwell Surgery	1
	Garden City Surgery	1
	Buntingford Medical Centre	2
St. Albans	Parkbury House	5
	Maltings Surgery	8
	Elms Medical Practice	2
	The Lodge Surgery	3
	Midway Surgery	1
	Hatfield Road Surgery	1
	Summerfield Health Centre	1
	The Village Surgery	3
Stevenage	King George Surgery	2
	Stanmore Medical Group	5
	Chells Surgery	1
	Manor House Surgery	1
Three Rivers	Abbotswood Medical Centre	1
	Vine House Surgery	1
	The Consulting Rooms	1
	Gade Surgery	2
	Baldwins Lane Surgery	1
	New Road Surgery	1

Watford	Bridgewater Surgeries	4
	Watford Health Centre	3
	Suthergrey House Medical Centre	1
	Garston Medical Centre	1
	Sheepcot Medical Centre	1
	Callowland Surgery	1
Welwyn Hatfield	Lister House Surgery	2
	Moors Walk Surgery	2
	Garden City Practice	3
	Potterells Medical Centre	1
	Burvill House Surgery	1
	Hall Grove Surgery	1
	Bridge Cottage Surgery	2
Other	University of Hertfordshire Medical Centre	1

Let's Talk about the Menopause:

The Views and Experiences of Women living in Hertfordshire

Engagement: May – July 2023

healthwatch Hertfordshire

Authors: Asha McDonagh and Chloe Gunstone

Contents

About Healthwatch Hertfordshire

Healthwatch Hertfordshire (HwH) represents the views of people in Hertfordshire for health and social care services. We provide an independent consumer voice for evidencing patient and public experiences and gathering local intelligence with the purpose of influencing service improvement across the county. We work with those who commission, deliver and regulate health and social care services to ensure the people's voice is heard, and to address gaps in services quality and/or provision.

About the Hertfordshire and West Essex Integrated Care System (ICS)

The Hertfordshire and West Essex Integrated Care System (ICS) was established as a statutory body on 1st July 2022. Integrated Care Systems are geographically based partnerships that bring together providers and commissioners of NHS services with local authorities and other local partners to plan, coordinate and commission health and care services[1]. The Hertfordshire and West Essex ICS is made up of two key bodies – an Integrated Care Board (ICB) and Integrated Care Partnership (ICP).

Integrated Care Board (ICB)

The Integrated Care Board (ICB) is an NHS organisation responsible for planning and overseeing how NHS money is spent across Hertfordshire and West Essex, with the aim of joining up health and care services, improving health and wellbeing, and reducing health inequalities. The board of the ICB includes representation from NHS trusts, primary care and from Hertfordshire County Council and Essex County Council[2].

This report will be sent to the Hertfordshire and West Essex ICB Primary Care Board to inform how primary care services can further support women during the menopause.

Integrated Care Partnership (ICP)

The Integrated Care Partnership (ICP) is made up of representatives from different organisations involved in health and care. This includes NHS organisations, local authorities and the Voluntary, Community, Faith and Social Enterprise (VCFSE) sector. The partnership is responsible for developing an Integrated Care Strategy which will set out the priorities for Hertfordshire and West Essex for the next 10-20 years[3].

[1] Integrated care systems: how will they work under the Health and Care Act? | The King's Fund (kingsfund.org.uk)
[2] Health and wellbeing decisions – Hertfordshire and West Essex Integrated Care System (hertsandwestessexics.org.uk)
[3] Health and wellbeing decisions – Hertfordshire and West Essex Integrated Care System (hertsandwestessexics.org.uk)

Hearing Patient Views about Primary Care in Hertfordshire and West Essex

Healthwatch Hertfordshire and Healthwatch Essex have been commissioned by the Hertfordshire and West Essex Integrated Care System (ICS) Primary Care Workstream to undertake a series of engagement projects. The aims of the engagement projects include:

- Gathering lived experiences to feed directly into the Hertfordshire and West Essex ICS Primary Care Workstream
- Supporting and enabling the Hertfordshire and West Essex ICS to achieve wider participant engagement
- Engaging patients and the public on programmes covering key priorities and areas of importance at a regional and local level
- Making recommendations to the Hertfordshire and West Essex ICS Primary Care Workstream so improvements can be implemented

Using patient and public feedback, each engagement project will focus on improving the relevant service(s) within different areas of primary care by making recommendations to the Hertfordshire and West Essex ICB Primary Care Board.

From May 2023 to August 2023 the Director of Primary Care Transformation at the ICB has requested Healthwatch Hertfordshire and Healthwatch Essex to explore whether women have looked for information, advice, or support from primary care services for the menopause, and if so, whether they have felt adequately supported.

Background

What is the Perimenopause/Menopause?

The menopause is when an individual's periods stop due to lower levels of a hormone called oestrogen[4]. The menopause typically occurs between the ages of 45 and 55, with the average age being 51 years old in the UK[5]. However, **1 in 100** people will experience menopause before the age of 40 years[6].

The menopause can happen naturally or for reasons such as surgery to remove the ovaries (oophorectomy) or the uterus (hysterectomy), cancer treatments like chemotherapy or a genetic reason. Sometimes the reason is unknown[7].

The charity Wellbeing of Women estimates there are around **13 million** women in the UK who are perimenopausal or menopausal[8]. This equates to around a third of the UK female population[9].

The perimenopause is when someone has symptoms of the menopause but their periods have not stopped[10]. The perimenopause is caused by fluctuating oestrogen, which impacts women's menstrual cycle, shifting their regular period to a more erratic cycle. Perimenopause ends when someone has not had a period for 12 months[11].

The length of the perimenopause also differs from woman to woman[12]. Although some women will experience symptoms of the perimenopause for a couple of years, some women can experience this stage for over a decade[13]. Some women can start the perimenopause as early as their twenties, but most women will start it in their mid-40s[14].

Some people who are trans or non-binary will also experience perimenopause symptoms due to the hormones they take[15].

What are the symptoms?

Every women's experience of the menopause is distinct and varied. There are over 30 symptoms of the menopause, which are physical and mental[16]. Although 1 in 4 women go

[4] Menopause - NHS (www.nhs.uk)
[5] https://www.nhsinform.scot/healthy-living/womens-health/later-years-around-50-years-and-over/menopause-and-post-menopause-health/menopause
[6] Menopause factfile | Local Government Association
[7] Menopause - NHS (www.nhs.uk)
[8] committees.parliament.uk/writtenevidence/39395/pdf/
[9] committees.parliament.uk/writtenevidence/39395/pdf/
[10] Menopause - NHS (www.nhs.uk)
[11] Menopause - NHS (www.nhs.uk)
[12] Perimenopause: Rocky road to menopause - Harvard Health
[13] https://www.health.harvard.edu/womens-health/perimenopause-rocky-road-to-menopause#:~:text=Perimenopause%20varies%20greatly%20from%20one,many%20have%20no%20bothersome%20symptoms.
[14] Perimenopause - Symptoms and causes - Mayo Clinic
[15] How do hormonal changes affect the trans and non-binary community? – Menopause in the Workplace | Henpicked
[16] https://menopausesupport.co.uk/?page_id=60

through the menopause without any or very few symptoms, **1 in 4** will have symptoms so severe that they have an adverse impact on their physical and mental wellbeing[17].

Common symptoms of the menopause include[18]:

· Hot flushes
· Night sweats
· Dizziness
· Fatigue
· Headaches
· Recurring UTIs
· Stiff joints, aches, and pains
· Heavy periods
· Insomnia
· Itchy skin
· Osteoporosis
· Weight gain
· Anxiety
· Memory loss
· Depression
· Reduced concentration
· Brain fog

The Fawcett Society surveying over 4,000 women found that most women (**77%**) find at least one menopause symptom "very difficult" while **44%** experience three or more symptoms that are severe[19]. Moreover **84%** of women find sleeping difficult, **73%** experience "brain fog", and **69%** suffered from anxiety or depression[20].

They also found that the menopause impacted women's ability to work, with most women receiving very little support in the workplace, and on some occasions facing discrimination[21]. Shockingly, **80%** of women surveyed said their workplace has no basic support for them, and **41%** said they have seen menopause or menopause symptoms treated as a joke by people at work. **39%** of women going through the menopause cited anxiety or depression as the main reason on their sick note rather than share their menopause status[22].

It is also important to note that not all women have the same experiences of the menopause. The Fawcett Society fund that **22%** of disabled women left their jobs because of severe menopause symptoms, and **45%** of women from ethnically diverse

[17] https://menopausesupport.co.uk/?page_id=60
[18] https://menopausesupport.co.uk/?page_id=60
[19] Landmark Study: Menopausal Women Let Down by Employers and Healthcare Providers | The Fawcett Society
[20] Landmark Study: Menopausal Women Let Down by Employers and Healthcare Providers | The Fawcett Society
[21] https://www.fawcettsociety.org.uk/news/landmark-study-menopausal-women-let-down-by-employers-and-healthcare-providers
[22] https://www.fawcettsociety.org.uk/news/landmark-study-menopausal-women-let-down-by-employers-and-healthcare-providers

backgrounds said it took many appointments for their GP to connect their symptoms with the menopause, compared to **30%** of White women.

The above statistics highlight the extent to which women are stigmatised and discriminated against as a result of the menopause and menopausal symptoms. Historically it has been conceptualised as a difficult, shameful and secretive stage and widely taken to signal the end of a women's social value[23]. This has led to physical and mental health symptoms associated with the menopause being insufficiently acknowledged or addressed by healthcare services, the workplace and society in general[24].

Positively, in recent years the UK has been experiencing what one academic has termed the "menopausal turn"[25] – with campaigns such as #MakeMenopauseMatter movement, expanding the school curricula, medical training to educate about the menopause, and high-profile celebrities such as Davina McCall publicly discussing the menopause and raising awareness. This increase in publicity has encouraged more women to access support, with an increase of **60%** in menopause supplement sales in 2020 and women are now calling for greater support from health care services[26].

Accessing Support

GPs are typically the first point of contact for women experiencing menopausal issues[27]. Currently, GPs receive no formal training on the menopause, which some argue that this lack of training and education leads to some women being misdiagnosed, receiving inadequate support, and lacking trust in healthcare professionals to understand and treat their symptoms appropriately.

Research by Joyce et al (2022) found that women felt that GPs had an inadequate understanding and/or awareness of the perimenopause/menopause, with many having to return several times following inaccurate diagnoses and/or incorrect prescriptions. Many also felt unsupported, undermined and disrespected by GPs, leaving women lacking confidence in healthcare services to get the help they need[28]. In some cases, women had no choice but to turn to the private sector and pay for treatment[13].

Similarly, research by Dintakurti et al (2022) identified that **52%** of GPs felt that their GP training did not equip them with the right tools and support to treat and manage women presenting with menopausal symptoms, and **78%** felt that training on the menopause and related health issues needs to be improved[29]. Although it is positive that GPs recognise

[23] 'Everything you need to embrace the change': The 'menopausal turn' in contemporary UK culture - ScienceDirect
[24] https://www.sciencedirect.com/science/article/pii/S0890406523000154
[25] https://www.sciencedirect.com/science/article/pii/S0890406523000154
[26] https://www.sciencedirect.com/science/article/pii/S0890406523000154
[27] An online survey and interview of GPs in the UK for assessing their satisfaction regarding the medical training curriculum and NICE guidelines for the management of menopause - PMC (nih.gov)
[28] https://journals.sagepub.com/doi/10.1177/17455057221106890
[29] https://journals.sagepub.com/doi/10.1177/20533691221106011

they need more information and knowledge, it appears this action is yet to be taken in some practices.

It is important that healthcare professionals are able to appropriately support women through the menopause, as many have not received any education or information about the menopause and/or its related symptoms. The research by Joyce et al (2022) found that **90%** of respondents were not taught about the menopause at school and over **60%** did not feel knowledgeable about menopause[30]. Concerningly, **68%** of women surveyed only researched menopause once their symptoms had started. As such, women are often reliant on healthcare services to provide them with the information and support they need.

Concerningly, The Fawcett Society found that **45%** of women have not spoken to their GP surgery about their symptoms[31]. Shame and stigma often prevent women from seeking help for the menopause, with some women stating that they are too embarrassed to discuss the menopause, let alone seek clinical help. This is echoed by Jemima Olchawski, Chief Executive of The Fawcett Society, who commented that: "Too often menopause symptoms have been dismissed as a joke and HRT has been labelled a lifestyle drug.....Faced with that misinformation, is it a wonder that only half of women are even seeking help from their GP?"[32]

Many women despite suffering symptoms are also reluctant to access an already overburdened NHS and feel as if they can endure their symptoms for now[33]. A lack of knowledge about the menopause and an underestimation of the severity of symptoms are also factors that prevent women from seeking clinical help for the menopause[34]. This lack of preparedness means many women struggle to find the confidence to seek help when they need it. Lastly, given the lack of education and awareness on the menopause, many women have commented that they did not know what support NHS services could offer them[35]. However, it is also worth noting that some women's symptoms are not severe enough for them to access support and some women can confidently self-manage their symptoms without the support of primary care[36].

Project Aims

- To investigate whether women going through the perimenopause/menopause are seeking help from primary care services and if not, the reasons for this.
- To explore whether women are being diagnosed with the perimenopause/ menopause and if the treatment they are getting is appropriate and timely.

[30] An online survey of perimenopausal women to determine their attitudes and knowledge of the menopause - PMC (nih.gov)
[31] Landmark Study: Menopausal Women Let Down by Employers and Healthcare Providers | The Fawcett Society
[32] Menopausal women lack basic support, landmark survey finds | Menopause | The Guardian
[33] The British Menopause Society response to the Department of Health and Social Care's call for evidence to help inform the development of the government's Women's Health Strategy - British Menopause Society (thebms.org.uk)
[34] appg-menopause-fsrh-bms-rcog-joint-response-sept-2021.pdf
[35] Briefing (healthwatchwarrington.co.uk)
[36] appg-menopause-fsrh-bms-rcog-joint-response-sept-2021.pdf

- To consider whether women trust their GP and feel supported with perimenopause/ menopause.
- To discover what information, care, and treatment women want during the menopause.

Methodology

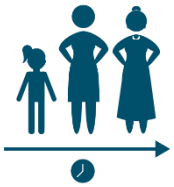
To explore the above aims, we ran an online survey to hear from women living in Hertfordshire. Respondents had the option to request the survey in an alternative format to suit their needs and/or to contact us for support.

Given the potentially sensitive nature of this topic, we decided that an online survey would be the most feasible method of data collection that would allow women to talk candidly about their lived experience and the challenges they have faced.

The engagement period ran from May to July 2023. The survey was promoted via social media and shared with NHS and other statutory services and the Voluntary, Community, Faith and Social Enterprise sector across Hertfordshire to share and distribute via their networks, contacts and social media channels.

Demographics

We heard from ***560 women*** who are either currently going through or have experienced the perimenopause/menopause.



Overall, **10%** of women experienced an early menopause, with **2%** of women experiencing symptoms under the age of 30, and **8%** of women experiencing symptoms between the ages of 30 and 40.

60% experienced symptoms between the ages of 40 and 50 and **26%** of between the ages of 50 and 60. A further **4%** were unsure as to when they started the perimenopause/menopause.

80% are White British and **17%** were from an ethnically diverse background[37].

20% are a carer.

23% have a long-term condition.

11% have a disability.

Trans and non-binary people can experience the menopause due to the hormones they take. However, we only had those who identify as a woman filling in this survey, so the term 'woman' has been used throughout.

Symptoms

The symptoms women experienced during the perimenopause/menopause were:

- Brain fog or memory problems: **78%**
- Difficulty sleeping: **74%**
- Hot flushes: **68%**
- Anxiety or depression: **68%**

[37] Ethnicities engaged with included: Arab, Bangladeshi, Chinese, Indian, other Asian/Asian British backgrounds, Black African, Black Caribbean, Asian and White, Black African and White, Black Caribbean and White, other Mixed/Multiple ethnic backgrounds, White Irish, White Polish, White Italian, and other White backgrounds.

- Mood swings: **61%**
- Aches and pains: **60%**
- Changes in weight: **60%**
- Changes to their sex drive: **56%**
- Irregular or inconsistent periods: **51%**
- Palpitations: **42%**

Other symptoms included worsening of pre-existing conditions, as well as hypermobility , Rosacea, difficulty maintaining blood sugar, eczema, hair loss, tinnitus, migraines, cold flushes, shivering, allergies, digestive issues, IBS, sore breasts, night terrors, and acne to name some examples. Some respondents experienced symptoms so severe that they significantly impacted their day-to-day life, as well as their physical and mental wellbeing.

"Irregular or inconsistent periods – very heavy bleeding leading to no longer being able to sit in meetings for more than an hour and bleeding for 3 weeks in every 4."

"Digestive issues, bloating, vaginal dryness, osteoporosis, tinnitus/itchy ears, word blindness, losing half my vocabulary which impacts my work."

"Unable to find common words mid conversation, feeling that I am completely useless, losing train of thought."

"Itchiness, overarching tiredness, inability to do anything on a daily basis, constant tears and thoughts and feelings of suicide to the point where it was all I thought about for months."

Support

79% looked for advice, information or support from **NHS services** to help them with the menopause/perimenopause. Of this percentage:

76% accessed support from a GP.

17% accessed support from a practice nurse.

9% spoke to a pharmacist.

However, **21%** of respondents **did not** access support from **NHS services**. Of this percentage, **18%** sought help from elsewhere:

47% found support from various online resources, including the NHS website, online support groups and forums, and social media.

6% accessed private healthcare.

10% spoke to their friends or family for support.

A few respondents used self-help books, newsletters and accessed support for their employer.

Of the **21%** of respondents who did not seek help from NHS services for the menopause/perimenopause, the majority (**60%**) said this was because they did not think their symptoms were severe enough. Respondents shared that although they had some symptoms, they were mild and had little impact on their day-to-day life. As such, respondents felt they could self-manage their symptoms without needing additional support from a GP or another primary care service.

"I never reached the point where I felt I was not coping with it, so I did not think I needed to ask for help. It was just an inconvenience to occasionally strip the bed in the morning because I had had night sweats."

"There was no reason to seek advice because my symptoms were so mild."

"I thought my symptoms weren't (and currently aren't) having a big enough impact on my day-to-day functioning."

"I experienced minimal symptoms which I self-manage."

Similarly, **18%** of respondents said they did not need support right now but may consider seeking support from NHS services or elsewhere if their symptoms worsened or start impacting their daily functioning and/or their physical health or mental wellbeing.

"I have very mild symptoms and I don't need to use HRT. The information I have got online has given me everything I needed. If my symptoms were more troublesome, I would speak to my GP."

"It's early days so I will wait until I require treatment."

"Other than very irregular periods which are manageable, I have not yet needed any further support."

33% said they have not sought support because it would be too difficult to access NHS services. Respondents commented that it is hard to contact their GP practice and often very challenging to get an appointment, especially as it would be considered non-emergency. Some respondents also shared that their working hours are not compatible with their GP practice's opening times and/or they would struggle to get the time off work to attend.

"It's so hard to get a doctor's appointment nowadays and I work full time so can't spend ages hanging on the phone. Last phone call to get an appointment I was waiting for 90 minutes to get through."

"Waiting times are too long. I am unable to work, menorrhagia and period between 10-21 days."

"I can't get to see my GP for a medical emergency so there is no way they will be available for a 'general chat'."

31% said they did not think they would get the support they need from NHS services. Of this percentage, many respondents believed that clinicians would not listen to them or take them or their symptoms seriously. Respondents also felt that clinicians would not be compassionate and would have an inadequate understanding and/or awareness of the menopause to provide the support they need.

"I feel like I will be told I am suffering with depression which I am not."

"Services are not geared to support women with menopausal symptoms."

"It's very difficult to get a GP appointment and many are not sympathetic or knowledgeable."

Some respondents felt reluctant to seek help from NHS services after hearing about the poor experiences of their friends and family and the struggles they have faced when accessing support, including not being given the help they needed and clinicians lacking empathy and education about the menopause.

"I also have a lot of friends who are struggling to get the support they need or are fobbed off with anti-depressants or felt ridiculed by middle aged male doctors who do not take symptoms seriously and have made them feel a burden and not listened to. For this reason, I have not sought additional support until any symptoms become severe."

"Friends who have gone through similar have had a lot of problems getting help so I have just been getting on with it."

" From friends and relative's experiences there is also a lack of knowledge/empathy especially in older male GPs around menopause and its issues which puts me off seeking advice."

"I have heard from other friends that they are struggling to get appointments with GPs to discuss their symptoms, and when they do speak to a GP they are not taken seriously. Or they are offered anti-depressants which they do not want to take."

Some respondents were also scared they would not be able to get Hormone Replacement Therapy (HRT), following the recent shortage or felt clinicians would be hesitant to prescribe this to them.

"It's a lottery which GP you get and if they are aware of menopause and the best way to help. I know many friends who have been prescribed antidepressants instead of HRT and friends who have been given oestrogen without progesterone etc. I am seriously thinking about contacting GP regrading HRT, but there is currently a shortage of many drugs, and it worries me that I will come to rely on a drug that may become unavailable or be very difficult to get hold of that sounds more stressful than symptoms!"

"I was suicidal and in a terrible state, hot flushes were unbearable, nearly lost my job, had a breakdown. Doctors will refuse HRT, I had tried everything else, therapies and counselling."

"I tried to speak with a GP numerous time and was told to do my research and that HRT is linked to cancer."

11% wanted to use alternative therapies, with many of these respondents commenting that they would like to find alternatives to HRT and other medications such as anti-depressants to manage their symptoms. For some, this is because they have concerns about the side effects of using HRT and its potential link to certain cancers, while others have an existing health condition or family history which means that HRT is not an option for them. A few respondents said they have minimal symptoms which they felt they could self-manage using other methods, while others have chosen to use alternative therapies because they believe healthcare services cannot provide them with the type of support they want or need.

"I'm not aware of anything that a GP can offer that isn't HRT and I don't want to do that. I have bought supplements that claim to help but I'm not sure they do. However, I'm now to scared to stop taking them in case I feel even worse."

"GPs are impossible to get non-emergency appointments with and from experience rarely have anything to offer on alternative therapies, due to family history I don't wish to utilise the standard HRT route, so I have been looking online myself for other suggestions/alternatives."

"GP doesn't have the type of support I want."

"I did once mention my symptoms of menopause briefly to a lady GP and all she did was try to push HRT on me which I knew I didn't need or want as my symptoms were not that severe. She wasn't interested in anything further."

Similarly, **15%** of respondents said they have chosen to look online for support, and do not feel the need to use healthcare services. Of these respondents, many had mild symptoms. and/or in the early stages of the menopause but would consider accessing help from NHS services if their symptoms became more severe.

"I have been looking at various information online and taking note of the symptoms but as I am aware, if my periods are still occurring even if they are irregular, I will not be able to get any assistance as yet until my periods have stopped for a minimum of 12 months."

"At the moment my symptoms are fairly mild, albeit wide ranging. I am doing lots of online research as it is difficult to access appointments, but I will push for this if my symptoms become more severe."

Positively, just **6%** of respondents said they have not accessed support from NHS services because they have concerns about stigma or feel ashamed or embarrassed. Most of these respondents were worried that clinicians would not treat them with empathy or respect, rather than concerns stemming from wider factors such as cultural norms.

"I think that it affects women more than one realises and it is embarrassing to admit that you are suffering from brain fog etc."

"There is a certain stigma in asking for help, our mothers, colleagues, friends may have appeared to have managed with their symptoms, there is a feeling that you just have to get on with it."

"Embarrassment, thinking that the symptoms would pass on their own."

Some respondents shared that they do not want support for their symptoms because they view the perimenopause/menopause as a natural part of the aging process. Likewise, others expressed that they are able to cope with their symptoms without help from healthcare services. In a few cases, this was a generational issue, with many women commenting they are from a generation that 'just gets on with it'.

"I'm from a generation which just gets on with it and manages as best you can/ I am capable of coping with this myself as I did with puberty."

"As it's a natural cycle of life for women, I have accepted the various changes that I have experienced and I would not wish to take medication for it. I prefer to deal with it myself."

Many were unsure if they were going through menopause or were unaware of the treatment options that are available.

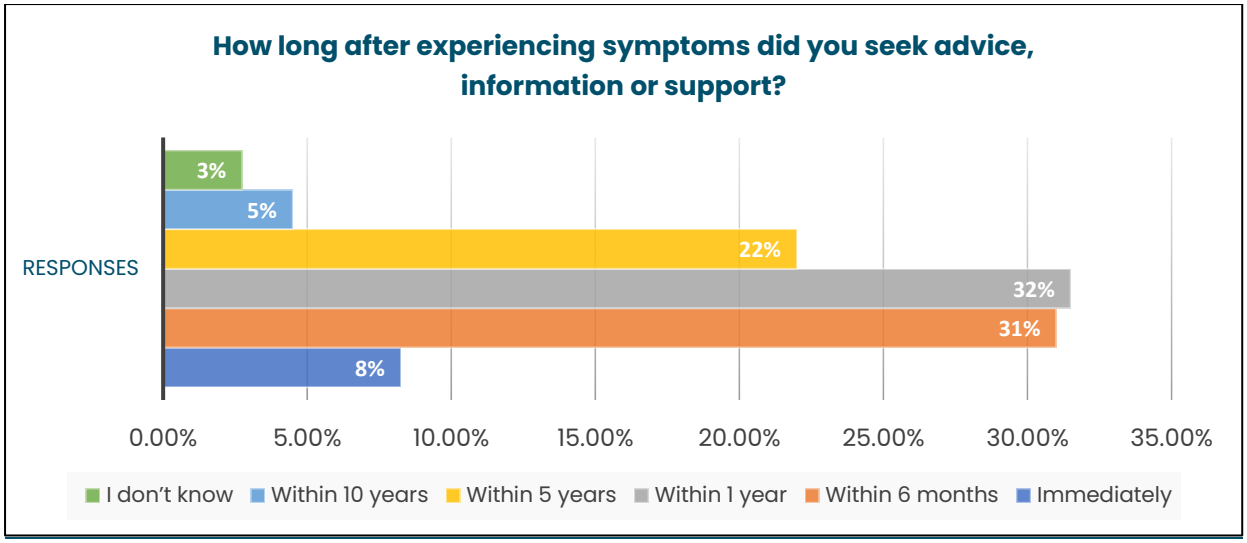
"I wasn't aware of all the symptoms and their links to menopause."

"I didn't think there was any treatment for it."

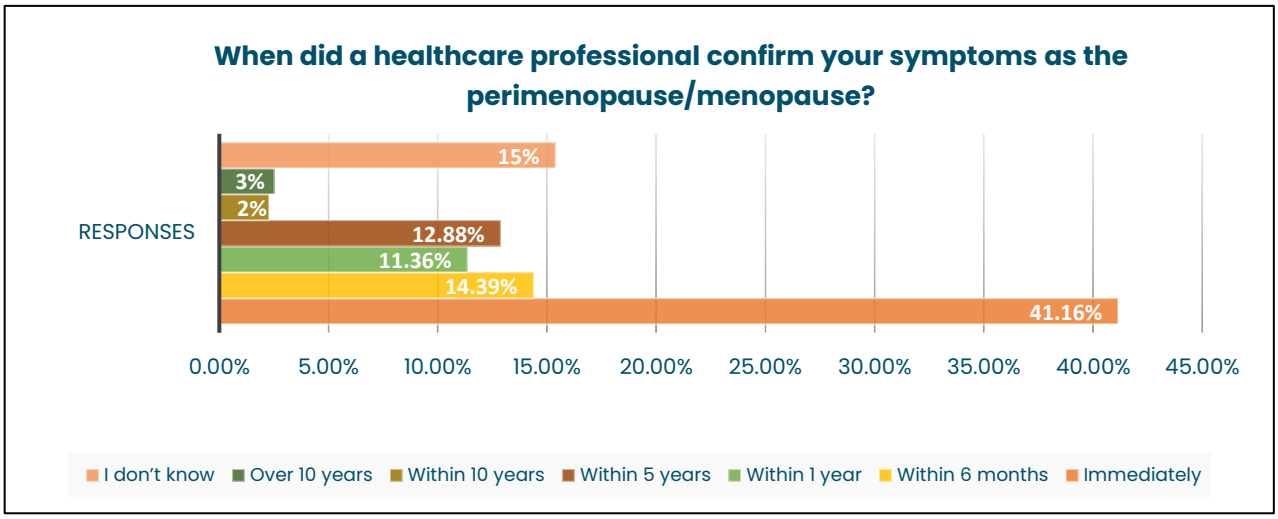
"I had a hysterectomy at 38 and have never been sure if my symptoms were menopause. It's only now that I look back on them that I feel they were."

Delayed Diagnosis and Treatment

Our research found that women often delayed getting help for their menopause symptoms. Only **8%** of women sought help for the perimenopause/menopause immediately. **31%** sought help within 6 months and **32%** sought help in a year. Concerningly, **22%** sought help within 5 years and **5%** within 10 years.



Even when respondents did seek support, in some cases it took a long time for a healthcare professional to confirm their symptoms were the perimenopause/menopause. Shockingly, **13%** of respondents shared that it took 5 years for a healthcare professional to diagnose the menopause, **11%** within a year and **14%** within 6 months. A further **2%** were diagnosed within 10 years and for **3%** it took over 10 years. However, for most respondents (**41%**) a healthcare professional recognised their symptoms immediately.



52% of women had to speak to healthcare professionals about their menopause symptoms multiple times. Many shared that they had to speak to several different doctors before they were taken seriously. This led to many women coming away from healthcare services feeling frustrated and unsupported and, in some cases, had to turn to private healthcare to get the support they needed. Although, it is important to note that once they had spoken to a healthcare professional who listened and understood, the majority of respondents felt very supported.

"I spoke to three different doctors, the last one understood and took my symptoms on board."

"It was recognised in the preceding years that I was perimenopausal, however when I went to ask for HRT the GP immediately confirmed my symptoms and was very supportive."

"I initially visited my GP 3 years ago where it was confirmed I was in perimenopause. I was not offered any treatment. After 3 years symptoms became unmanageable, and I visited by practice nurse who prescribed HRT."

Some respondents had to visit their GP practice multiple times after initially being misdiagnosed with other conditions, most commonly anxiety and depression, fatigue and digestive issues such as Irritable Bowel Syndrome (IBS) to give a few examples.

"I rang the doctor and talked about my symptoms saying I thought it was the menopause and was told I was depressed, and I needed antidepressants I said I didn't feel I was and did not get the antidepressants. I then got to the point where I couldn't manage at all and was off work sick and they gave me antidepressants and HRT. I took both as I was in such a bad place I felt as if I was having a break down."

"I was diagnosed with GAD."

"Still no joy with GP - all symptoms put down to depression and anxiety."

Factors Preventing Access to Support

Knowledge, Awareness and Information

When asked what prevented them from accessing support from healthcare services sooner, the majority of respondents said this was due to lack of knowledge, awareness and information about the menopause/perimenopause. Many did not associate their symptoms with the perimenopause or menopause, with some believing that their symptoms were related to their mental health and/or found it hard to differentiate whether their symptoms were the menopause or due to other external factors such as work and family.

"Physical symptoms not too bad. Didn't recognise that mental issues were in any way connected with the menopause - just thought I was going mad."

"I didn't realise my symptoms were connected with being perimenopausal, as at the time I didn't know anything about it."

"I was trying to determine if symptoms were due to external circumstances - effects of Lockdown, supporting family members that were struggling with mental health, changes in my own work etc...."

"I didn't realise in the early days that my symptoms were due to the perimenopause, there was very little information available at that time, I wish I had received help earlier."

"It took a while for me to be sure that I really wasn't imagining the brain fog - I thought I had started developing Dementia!"

"I wasn't clear how much perimenopause was affecting me as I was anxious and depressed about life events at the same time."

Linked to this, some respondents stated that they did not know that they were experiencing menopause until they had spoken to a friends and family. A few only became aware of symptoms of the menopause through the media.

"Wasn't sure what was happening to me, suspect it might have been going on for longer. Only when talking to others and education from TV programs such as Davina McCall did I realise I might be perimenopausal."

"I wasn't aware that my symptoms were related to menopause until I saw Davina McCall's TV programme."

Treatment from Clinicians

Many respondents said that they did not access healthcare services immediately due to the fear that they would be misdiagnosed, dismissed, or not taken seriously by healthcare professionals.

"I was worried about being believed at 43, I was judged as being too young to start the menopause."

"Didn't think I would be believed/taken seriously as I was only 41."

"I wasn't sure I would be taken seriously."

Some respondents did eventually see a healthcare professional, with many unfortunately having a poor experience which prevented them from seeking further help, despite having severe symptoms. Concerningly, a few respondents were told by healthcare professionals that what they were going through was a part of life, whereby you just "get on with it" and as a result were often refused any treatment.

"At an appointment I expressed how I was suffering and was told by a female doctor that 'We all have to go through it!' Therefore, felt I shouldn't bother anyone with it in future."

"I had hormone/period issues since late 20's and always felt 'fobbed off' with doctors as this is 'normal' apparently."

"Independent symptoms could be managed when all together became unmanageable so sought assistance. Then had 5 different GPs in 5 months. Last one responded appropriately."

Access

Access issues were a key barrier for women seeking support, with many emphasising the challenges they faced to get an appointment due to long waiting lists and difficulties getting through to their GP. Some respondents commented that they were too busy to seek help often due to their working hours, caring and childcare responsibilities. A few said they experienced symptoms during the COVID pandemic and as such, were hesitant to visit healthcare services for help.

"Difficulty getting an appointment and if I did used it for more 'urgent' concerns, unsure what the symptoms were."

"It was around COVID times so waited until it felt safer."

"I was too busy working, and my work hours were not compatible with accessing GP services."

"It is very difficult to get appointments with the GP. If you email, they say to use patches which often doesn't work, if you call, they do not answer the phone and it becomes daunting to make that call and to keep trying."

Some respondents said that they did not access support from NHS services because they did not know what types of treatment or support could be available to them. Others had concerns that their GP practice would only offer HRT which they did not want to have prescribed.

"I didn't expect any support."

"Fear of HRT."

"I Didn't really want to go on HRT."

Similarly, some respondents wanted to try alternative treatments such as nutritionists, herbal remedies, over-the-counter remedies, and exercises such as yoga, before seeking support for their symptoms from a mainstream medical professional.

"Tried alternatives before seeking medical help - nutritionist, herbal remedies, self-help Just tried over the counter remedies first."

"I tried natural remedies initially until it was clear that my symptoms were too severe for natural remedies to work."

"I felt it was better to cope with natural methods first."

Severity of Symptoms

Lastly, some respondents avoided seeking help from NHS services because they felt their symptoms were only mild and could be self-managed, with many commenting that they did not want to "make a fuss" and could "put up with" their symptoms, hoping they would eventually subside. A few respondents expressed they thought the menopause was just a "natural part of aging" that did not require any additional support. However, despite this, most of the respondents said they wished they had accessed help sooner.

"In early stages of perimenopause then symptoms were bearable it was only after periods stopped and I was a year into the menopause itself that they became unmanageable."

"I thought it was just part of getting older and have shamefully only realised recently that I don't have to put up with this crap, there is stuff which can help."

"Thought I'd 'sit it out' - didn't realise how long it went on for! Also didn't realise how much menopause peaks and troughs - you think you're over it then a different symptom comes along and reminds you you're not!"

"Symptoms seemed too sporadic initially and I felt like I could have been perceived as making a fuss. I wish I would have sought support sooner."

Group Spotlight

Women's experience of the menopause is distinct and varied. We found that women going through an early menopause find it harder to get diagnosis and support for the menopause.

Women who started the menopause under the age of 40 were far more likely to access healthcare services for advice, information, or support. However, it took significantly longer for healthcare professionals to recognise their symptoms as the perimenopause/ perimenopause/ menopause. Many of these respondents commented that they felt dismissed and had to fight for many years to have their concerns listened to and taken seriously by healthcare professionals.

84% of respondents under the age of 40 visited their GP practice, compared to **76%** of those aged over 40 years old.

32% of respondents under the age of 40 spoke to a practice nurse, compared to **14%** of respondents aged over 40.

16% of respondents under the age of 40 spoke to a pharmacist, compared to just **6%** of those aged over 40.

Despite being more proactive in accessing healthcare services about their symptoms, it took respondents under the age of 40 much longer to receive a diagnosis.

Under 40

- 37% were diagnosed immediately
- 14% were diagnosed within a year
- 16% were diagnosed within 5 years
- 12% said it took over 5 years to receive a diagnosis

Over 40

- 42% were diagnosed immediately
- 11% were diagnosed within a year
- 13% were diagnosed within 5 years
- 4% said it took over 5 years to receive a diagnosis

Lack of Knowledge

Many respondents said that they did not seek help for their symptoms because of their age, with respondents commenting that they were unaware that women could start the perimenopause in their late thirties and early forties.

"I wasn't sure if it was the menopause for a long time. Earlier on, people commented that I was too young (into my 40s), but didn't know what the moment was to know when to come in. Basically, I wasn't sure how or when to get help."

"I didn't realise my symptoms were perimenopause as I was only 38."

"I was only 40 years old so didn't think it was the menopause."

"I had a hysterectomy at 42 and believed that would be the end to all menstrual problems unaware that I would not only go straight into menopause but suffer with this at all a total misconception. And something that needs to be made more public."

Some respondents did not speak to a GP as they assumed or feared that they would be dismissed or not taken seriously due to their age.

"Because of my age (42) I worry I'll be 'fobbed off'."

"Didn't think I would be believed/taken seriously as I was only 41.

"Unsure of reception from GP. Unsure if I was too young."

Lack of Support

However, many women going through an early menopause shared that they did go to their GP about their symptoms but their concerns were dismissed by healthcare professionals because of their age, and in some cases were given the wrong treatment, such as anti-depressants.

"When I first went to see the GP aged under 40, I was told I was too young and sent away."

"My doctor told me that was 42 I was too young and so put me on anti-depressants."

"I was told I was too young at 39 after raising it with a nurse at another routine check up. I knew I would be put off asking for help."

"My age, no health professional imagined my symptoms could be due to early menopause."

What healthcare services are doing well and less well

When asked what healthcare services are doing well, **23%** of respondents did not think healthcare services were doing anything to support women during the menopause/perimenopause, and **14%** said they uncertain as to what healthcare services were doing to support them.

Often this was because they had a poor experience when accessing NHS services for help with their symptoms or had not tried to receive support the NHS so could not be sure as to what was working well and what could be improved.

"Not a lot - it seems to be a male orientated service, where women are treated as a problem."

"As far as my GP goes pretty much nothing. I requested a testosterone test due to lack of sex drive. Results came back normal. This was delivered by a receptionist with no additional information. I asked what get next as clearly the issue was still there. She said to get an appointment to see a GP. This is so difficult to arrange as you must ring in the morning for an appt that day and can never through. All pointless really and unless you are on top of it seems you are better off going private or doing your own research."

"In my case nothing as I had zero support from primary care. Everything I learned I found out for myself, and I was offered no treatment at all."

Staff Attitudes

Positively, some respondents had a good experience when accessing support from healthcare services for the menopause/perimenopause. **15%** of respondents praised healthcare professionals for treating them with kindness, sympathy and understanding. Of these respondents, many commented that healthcare professionals took the time to listen to their concerns and the symptoms they were experiencing, and provided them with excellent support, information and reassurance.

"The good doctor was very reassuring and knowledgeable – she didn't make me feel like I was going mad."

"I can only speak from my personal experience. My GP was supportive, understanding and stated from the offset that there is no "quick fix" and that we need to keep monitoring, adapting strength/type of HRT – it would seem that the support I have received from my female GP is rare. Certainly friends of my age have not had the support."

"I had a female GP (younger than me and not experienced menopause herself) – very sympathetic and helpful."

"When they take women's experiences on board, have time to listen and provide guidance with information that is relevant to each woman. I had a positive experience with my GP. She took the time to listen and provide information and was not dismissive of my current and/or future choices."

Although, **8%** of respondents felt that the care and treatment received is largely dependent on the healthcare professional you see and their knowledge, experience and expertise. Respondents commented that they had to speak to multiple healthcare professionals within their GP practice before they eventually got the care, treatment and support they needed. Some respondents also compared their experiences with between different GPs and in some cases compared their experiences to their friends and family, to illustrate that there is not equitable service.

"It depends which GP you get. I spoke to 3 different GPs (in the same GP practice) and 1 pharmacist. One GP (female) was really helpful and talked me through symptoms, what to expect, medication and non-medication approaches. The other 3 just wanted the conversation over quickly and just gave me medication and didn't talk me through the medication. The conversation with the pharmacist felt very uncomfortable."

"I think some doctors will listen and support you, but others lack knowledge and dismiss you."

"I had one GP in my practice that understood the symptoms and affects it was having on me personally, the other five did not consider the menopause as a diagnosis. Three thought it was a viral issue."

Greater Awareness

10% of respondents shared that healthcare services seem to be doing more to raise awareness of the menopause/perimenopause and its related symptoms, and to provide women with the information they need, for example by having leaflets and posters readily available in GP practices and pharmacies. Respondents also commented that some healthcare professionals appear to have with a renewed understanding and greater

awareness of the menopause/perimenopause, which many felt has been a result heightened media coverage.

"Research, upskilling and raising awareness – looking at it with renewed understanding and open mindedness."

"Raising awareness of the symptoms of the symptoms of the menopause to everyone."

"Seems to be taken more seriously than a few years ago. More mainstream support and conversation around it."

"I think media has heightened the country's awareness to menopause, GP surgeries I believe are becoming more aware due to this media coverage and listening to women to explore more options."

Treatment Options

12% of respondents said that healthcare professionals appear to be more willing to prescribe HRT, and to prescribe this medication more quickly than in the past – which for many of these respondents was incredibly helpful and important in helping them to manage their symptoms.

"Responding quickly with HRT."

"Giving HRT when requested by patient."

Similarly, **4%** of respondents commented that healthcare professionals were supportive in providing them with a range of treatment options to choose from, which made respondents feel listened to and maximised their agency and control in their own care.

"My GP outlined options to me and asked me what treatment/option I preferred and that made me feel in control of the situation."

"They gave me good advice to try alternative treatments at first due to history of female relatives in my family…They explained all the risks and benefits of HRT before I decided to go down this route."

Specialist Services and GPs

6% of respondents felt that it was encouraging to see that there are more GPs specialising in women's health, particularly the menopause/perimenopause. Respondents who were able to speak to a GP specialising in this area often had a far more positive experience, receiving the support and care they needed in a timely manner whilst being treated with respect and empathy. A few respondents also commented that their GP practice has run courses for women registered with the practice, providing them with information and tailored support for the menopause/perimenopause.

However, it is worth noting that some respondents felt that it is a "lottery" with some areas and GP practices providing excellent support, including the provision of specialist menopause clinics, while in other areas the care received appears to be inadequate in some cases.

"I am now getting excellent support from the GP specialist but it took years to get seen by her – other GPs just did not have the knowledge. I wish I had got this support 7 or 8 years earlier when problems first manifested."

"The Menopause course that was jointly run by 5 surgeries inviting a Consultant Gynaecologist, a Breast Cancer Nurse specialising in the menopause; a Personal Trainer; a Nutritionist and a GP who have a whole lesson on women's biology and changes etc before, during and after the menopause, PLUS at the end the opportunity to book and see a GP for an appointment if you still felt you needed it was fantastic."

"Now that I have access to the GP specialist things are going much better. She has personal experience of it, which is probably key!!"

"It's a lottery which GP you get and if they are aware of menopause and the best way to help."

Suggestions for Improvement

More Training and Specialist Support

When asked how healthcare services could better support women going through the perimenopause/menopause, the majority of respondents noted the need for greater education, information and training for healthcare professionals about the menopause/perimenopause and its related symptoms.

Some respondents said that, specifically, clinicians need to be more informed about how early women can start the menopause and have a greater understanding of the emotional impact of the menopause not just the physical effects. A few respondents also commented that the education and training received needs to be up-to-date, noting that some clinicians are sharing information that is outdated, particularly regarding HRT.

Linked to this, some respondents said they would like to see the provision of more menopause clinics, and for a greater number of healthcare professionals to specialise in the menopause and women's health.

"Train GPs to have a greater understanding about the physical effects of the menopause as well as the emotional/mental affects."

"All healthcare professionals, particularly GPs need UP TO DATE training. I was seen by a GP who scared me so much about being on HRT that I came off it, only to find out the information he was sharing was out of date and not relevant."

"Have menopause specialists available for appointments, prioritise women who are suffering with severe symptoms."

"Be much better informed themselves. I had many perimenopause symptoms for years and doctors never seemed to know what was going on until I educated myself and informed them and asked for HRT. I could have avoided many years of distress had all the GPs I spoke to just been better informed."

"More investment into women's health. All GPs to have training in menopause and for it to be mandatory that every GP practice has a at least one GP which specialises in menopause and women's health. It should also be mandatory for every GP practice to have a nurse practitioner who specialises in menopause and a menopause support group or at least know of a local support group to signpost women too."

More Empathy and Understanding

Following this, most respondents raised people would feel more supported through the menopause, and be encouraged to seek help from healthcare services, if clinicians listened to their concerns and treated them with greater compassion, understanding, and empathy, rather than dismissing their symptoms – which in many cases has led to misdiagnosis and respondents not receiving the medication, care and support they need. menopause, and be encouraged to seek help from healthcare services, if clinicians

listened to their concerns and treated them with greater compassion, understanding, and empathy, rather than dismissing their symptoms – which in many cases has led to misdiagnosis and respondents not receiving the medication, care and support they need.

"They should listen more, be more understanding. It can be a very worrying and emotional time for women, it can also coincide with children leaving for university so this can make emotions run higher."

"Be a bit more understanding, for those that are experiencing this at an earlier than average age, and to discuss options, rather than just tell you what it is, and then that's it."

"Listen to women when they report symptoms. Do not treat them as if they are being a nuisance or are hypochondriacs. Allow them to have some say in the treatment they would like to try."

"Be more supportive and less dismissive. I know 50% of the population goes through this, but that doesn't mean it has to be without help."

"Informed healthcare providers who are empathetic, listen and are interested in exploring the problems rather than dismissing my concerns."

More Information

Some respondents said that they would feel encouraged to seek support if there was more information about what support is available from healthcare services. Respondents suggested that healthcare services, such as GP practices and pharmacies, provide leaflets and posters about what the menopause is and how healthcare providers can support women through the menopause. For many, having access to this information would have enabled them to access support for their symptoms sooner.

"I think more advice/support to women about recognising perimenopausal/menopausal symptoms and knowing when to seek help. I think I struggled for far too long before I went to see my GP."

"Advertise more what different types of support are available."

"If GP surgeries/NHS send information leaflets to women on services women can access or initiate menopause check-ups and have information stands at pharmacists."

Some respondents wanted more information about HRT, as there is a lot of misinformation about the availability and side effects of HRT. A few respondents also wished their clinicians had a more in-depth discussion with them about taking HRT, including information about the potential side effects and risks. Although, the use of HRT does increase the risk of breast cancer, ovarian cancer and in some cases womb cancer, the risk is slight and for the majority the benefits outweigh the risks. In recent years, there has been a greater understanding of the level of risk involved when taking HRT.

"I would have liked more information about the various options on offer for HRT I was only offered pills and told there is a risk of breast cancer and heart disease when these finding are now debunked."

"More information on how to take HRT and what to expect. Issues re obtaining HRT prescriptions and costs (although now have pre-payment certificate for HRT which my GP did tell me about recently)."

"HRT can be addictive and you suffer serious withdrawal symptoms resulting in myself after 14 desperate months of trying all homeopathic remedies with no relief begging to go back on HRT to be refused despite offering to sign a disclaimer and telling GP I was going to purchase online. I had reached the end of my tether. I have just stopped in January 2023 after 14 years. Flushes sweats still very bad!!"

Contrary to this, a few respondents said that they would like healthcare services to offer more information about alternatives to HRT and the other treatment options available to them. In particular, respondents wanted more advice from clinicians about how they can manage their symptoms through living a healthier lifestyle. In addition, respondents who are not able to take HRT due to their family history and/or an existing medication condition felt they were not given enough information about the other ways they can try to alleviate their symptoms.

"I had breast cancer in my 40's, can't take HRT, not much information available to women in this position. Just gave me a drug that made me for much worse."

"More advice on alternative remedies and general wellbeing like following a specific diet."

"Discuss options other than offering anti-depressants Refer for more alternative therapies. Ensure there is an easily accessible menopause clinic. Give more proactive treatment."

More Personalised Care

Some respondents suggested that healthcare professionals could provide patients with more personalised care, tailored to their specific needs. Respondents felt that some healthcare professionals need to recognise that individualised treatment is needed, as experiences of the menopause/perimenopause can vary massively between women.

"Listen, understand not everyone is the same, ensure full range of treatment is available."

"Listen to our lifestyle and needs, do not assume we are all the same. offer alternative and accessible treatments."

Likewise, respondents would like healthcare professionals to adopt a more holistic approach when providing care and treatment, taking into account a range of different factors and not just the physical symptoms.

"Thinking more holistically about the symptoms and reassurance."

"In general, I believe there is not much knowledge about the menopause and HRT. I would like to see health care services offering specialist, holistic care with an understanding that menopause impacts every area of women's lives - social, emotional, physical and financial."

Perimenopause/menopause Consultations

A few respondents suggested that healthcare professionals could be more proactive in discussing the menopause/perimenopause with patients during their appointments, particularly routine check-ups and NHS Health Checks. Some felt introducing a. "perimenopause/menopause" consultation could be beneficial.

"Invite women for a "premenopausal/menopause" consultation with time to ask questions, health check/regular checks."

"Every woman to have a check-up at 40 to discuss the menopause, educate and check blood levels, BP and general wellbeing."

"Be more proactive when symptoms indicate perimenopause/menopause, invite the patient in for a full discussion about what help there is."

Linked to this, some respondents felt that healthcare professionals should offer follow-up appointments, so they can discuss with patients how any prescribed medication is working and/or how their symptoms are progressing. For many, continuity of care and the opportunity to discuss how their treatment was going, and if there are any other options, was very important.

"Follow up appointments to ask how things are going and give more advice if needed."

"Offer follow up appointments. I knew nothing, was given no information and thought you just had to put up with any symptoms and just cope."

"To follow-up medication, to see if it's helping and active monitoring - my treatment is still not right and unless I actively follow up its not sorted."

Group Support Sessions

Some respondents suggested that healthcare services could run support groups, workshops and/or information sessions, which would not only provide useful advice but also enable women to share their experiences, tips and advice, as well as providing women with a space where they can ask questions. As this survey has found, a few GP practices in Hertfordshire have launched similar initiatives, which appear to have been successful.

"Provide group sessions with women experiencing symptoms of menopause and perimenopause."

"Have a dedicated appointment scheduled around 45/50 years of age to discuss. This could be a group session to give information and could be the start of a local group at the same stage who could then support each other - bit like the anti-natal classes where friendships were formed."

Access to Healthcare Services

Unsurprisingly, many respondents said they would like healthcare services to be easier to access, including shorter waiting times for appointments, greater availability of appointments, and the ability to book an appointment outside of working hours. Some respondents shared that they have avoided using healthcare services, despite

experiencing menopause symptoms, due to the fear of further burdening an already overstretched NHS.

Some respondents also suggested that having a longer consultation with a healthcare professional would enable them to explore more treatment options and more time to discuss their symptoms and concerns. Having a face-to-face appointment rather than online or by video was also important to many respondents.

"Face to face appointments rather than everything being telephone calls where often are received when not in a private place and therefore difficult to discuss all symptoms."

"Making more appointments available, very difficult to make first appointment as not urgent."

"There is no time to discuss options, no face-to-face appointments offered, no blood tests to ascertain if it is menopause."

"Give more choice of appointment times for people who work or have family/carer commitments. I had to take whatever time was given I had no choice. Educate male professionals as well as female staff. I was late for an appointment with GP on one occasion as I was stuck in traffic, I was travelling from work in the day as that was the only available appointment. I called ahead to explain so that the GP could flex the appointments and I was told I may not get to see the GP and how it would be a waste of an appointment. I offered to sit and wait and would work around my GP."

Conclusion

In recent years, there has been a greater awareness and acceptance of the menopause. With this increased demand for healthcare services, the quality of NHS healthcare services needs to be enhanced This report presents some concerning findings regarding the care and support women are receiving going through perimenopause/menopause.

We found that many women are not seeking support from NHS healthcare services for the perimenopause/menopause. For some women, this is because they are not aware about how NHS services can support them with the menopause, and/or are fearful that they will not be listened to by clinicians and that their concerns will be dismissed as a result. Respondents also commented that NHS services are often too difficult to access, meaning many have avoided accessing care, despite the severity of their symptoms and the significant impact this is having on their day-to-day life. Younger women in particular seemed to have a more negative experience, with many stating that clinicians did not take them seriously and had to wait years and/or speak to multiple clinicians before finally receiving a diagnosis – leaving them to feel neglected and alone during this difficult time.

Many women entered the perimenopause unprepared and often did not have the knowledge to seek help from healthcare services, with many not connecting their symptoms to the menopause or attributing their symptoms to other conditions More information and education from NHS services are urgently needed to encourage women to seek support from healthcare services.

This report also highlights the lack of knowledge, understanding, and support some women are receiving from healthcare professionals. Despite visiting healthcare professionals with debilitating symptoms of menopause, many were left without a diagnosis or were misdiagnosed and in some cases even given the wrong medication. We found numerous reports of women visiting healthcare services multiple times and going through multiple GPs before getting a diagnosis, meaning that many women were left feeling lost, confused and unsupported.

Although many respondents noted that NHS services are starting to make improvements in supporting women during the perimenopause/menopause, respondents of this survey called for greater education, information and training for healthcare professionals, as well as more compassion, empathy and respect for what an extremely difficult time for many women can be.

Recommendations

We recognise that primary care services, especially GP practices, are under immense strain and pressure. However, it is important that women are appropriately supported by these services during the perimenopause/menopause.

Based on the findings outlined in this report, it is recommended that the Hertfordshire and West Essex ICB Primary Care Workstream should encourage primary care services and the ICB to take forward the following recommendations.

Our research found that healthcare providers need to work on the diagnosis and treatment of the menopause. Our recommendations focus both on increasing awareness of the menopause so that women seek support and improving the advice, support, and treatment women receive from healthcare services.

Information

1. Providing information and resources (such as posters and leaflets) in GP practices and on GP practice websites, outlining the signs of the menopause and what support NHS healthcare providers can offer. Leaflets and posters could also be provided in pharmacies to extend the reach.

2. Signposting to local and national groups and charities supporting women during the menopause by providing information and resources in GP practices, pharmacies and on GP practice websites.

Staff Training

3. Clinical staff should receive more training, information and education on the menopause.

4. Every GP practice should work towards having a healthcare professional who specialises in the menopause/women's health.

5. If a GP practice has a clinician who specialises in this area, this should be signposted to on the GP practice website and mentioned to patients requesting an appointment about menopausal symptoms.

Communication

6. Clinicians should assess women If they come in with symptoms of the menopause, no matter what age they are.

7. Clinicians should take young women seriously, offering them blood tests when they come in with menopause symptoms.

8. Clinicians should treat women going through the menopause with kindness, respect, and take their concerns and symptoms seriously. Clinicians should be particularly mindful when discussing potential menopausal symptoms with younger women.

Support

These recommendations indicate what good practice looks like. However, we recognise the pressures and challenges healthcare providers, particularly GP practices are facing.

9. Clinicians should provide care that is personalised and specific to the individual.

10. Clinicians should take a more holistic approach to treating the menopause, taking into account the patient's physical, psychological and social needs.

11. Clinicians should provide a wider range of treatment options, enabling women to choose what medication and/or treatment is right for them.

12. Clinicians should signpost patients to local and national groups/charities supporting women during the perimenopause/menopause.

13. Clinicians should discuss the menopause at routine check-ups and NHS Health Checks.

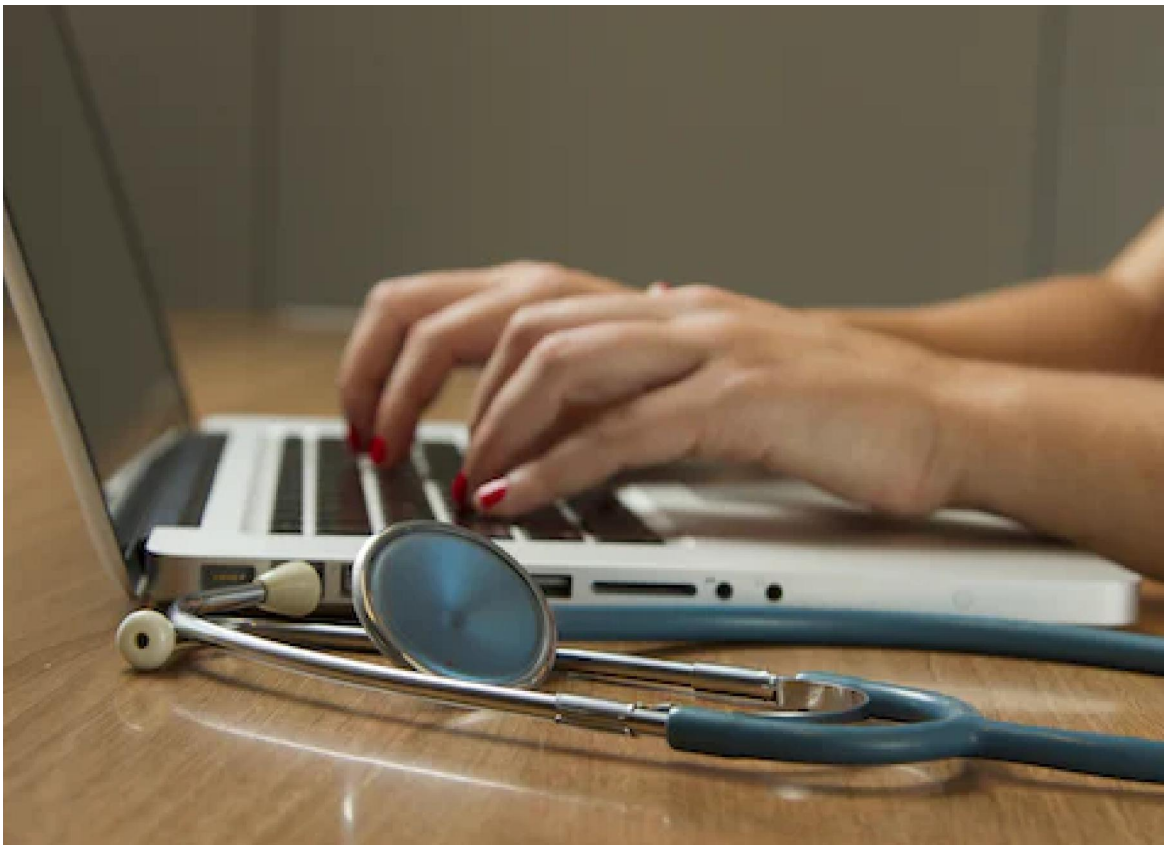
Access

14. Continuing to improve telephone systems to reduce delays and waiting times.

15. Offering greater flexibility in contact hours and opening hours to account for people who work and/or have caring responsibilities.

16. Offering greater choice in appointment types to enable patients to get the support they want and need.

Experiences of Cervical Screening in West Essex.



Sara Poole
Healthwatch Essex Information & Guidance Officer
For Hertfordshire & West Essex Integrated Care Board
June-September 2023

Contents

1.0 Introduction

1.1 Healthwatch Essex

Healthwatch Essex is an independent charity which gathers and represents views about health and social care services in Essex. Our aim is to influence decision makers so that services are fit for purpose, effective and accessible, ultimately improving service user experience. We also provide an information service to help people access, understand, and navigate the health and social care system. One of the functions of a local Healthwatch under the Health and Social Care Act 2012, is the provision of an advice and information service to the public about accessing health and social care services and choice in relation to aspects of those services. This document was revised in July 2022 and the role of Healthwatch was further strengthen as a voice of the public with a role in ensuring lived experience was heard at the highest level.

The Healthwatch Essex Information and Guidance team are dedicated to capturing the health and social care experiences people in Essex are meeting daily. The team respond to enquiries relating to health and social care and are equipped through training, to offer specific information to the public or other professionals. The team are well placed to listen, reflect on and support people to share complex experiences such as the one's shared in this report.

1.2 Background

Healthwatch Essex were approached by Hertfordshire and West Essex ICB to undertake a series of projects focussing on the lived experiences of people in the area in relation to their health, care and wellbeing. Two projects are selected per calendar quarter for in depth engagement, with the production of a report based on this engagement.

1.3 Acknowledgements

Healthwatch Essex would like to thank all the members of the public who took part in this project through the survey and interviews. Our thanks are also made to those individuals who took the time to meet with us and share their personal stories.

1.4 Terminology

CIN - Cervical intraepithelial neoplasia (CIN) is a term that describes abnormal changes of the cells that line the cervix.

HPV -Human papillomavirus.

ICB – Integrated care Board.

LLetz procedure -large loop excision of the transformation zone (LLETZ).

NCT – National Childbirth Trust.

PCT -Primary Care Trust.

1.5 Disclaimer

Please note that this report relates to findings and observations carried out on specific dates and times, representing the views of those who contributed anonymously during the projects time frame. This report summarises themes from the responses collected and puts forward recommendations based on the experiences shared with Healthwatch Essex during this time.

2.0 Purpose

The aim of this project is to gather people's lived experience of accessing and using the cervical screening programme across west Essex.

2.1 Engagement methods

We connected with a wide range of organisations and services in the execution of this project, including Essex County Council, Rainbow Services, Primary Care, community and voluntary services working with homelessness, addiction and mental health, our Ambassadors and carers support, in order to share details of our project and our Facebook page and website link requesting women and people with a cervix for their feedback and lived experience regarding the cervical screening process. We also shared this request to numerous local Facebook groups in the west Essex footprint. The Facebook posts reached over 80,000 residents across this area.

The survey link was also emailed to numerous groups and organisations across west Essex including:

Harlow Latton Ladies Group

National Women's Register-Saffron Walden

Essex Women's Institute

Essex Ladies Golf Club

West Essex Cricket Club

Essex Bowling Association

Tye Green Indoor Bowls Club

Changing Pathways-DV support

Essex Pole and Tone

Stanstead Mountfitchet parish council

NCT groups

Epping forest Outdoor Group

Epping Bowls Club

Epping Art Society

Life Church Epping

Women 4 Women Essex

New City College

Harlow College

Saffron Walden Council

Great Dunmow Council

Ongar Town Council

North Weald Bassett parish council

Epping Forest Child and Family Wellbeing Team

Home Start Essex

Support 4 Sight

Rainbow Services

Harlow Salvation Army

Streets 2 Homes

2.2 The Survey

We devised a survey asking women and people with a cervix to complete it, answering questions about their cervical screening experience. We were looking for positive and negative lived experiences.

59 people completed the online survey and around half of them offered a one-to-one interview so that they could share more details about their experiences.

Question 1:

Do you receive a letter inviting you to attend a cervical screening appointment?			
Answer Choices		**Response Percent**	**Response Total**
1	Yes	95.74%	45
2	No	4.26%	2

Question 2:

Do you attend your cervical screening invitation?			
Answer Choices		**Response Percent**	**Response Total**
1	Yes	84.78%	39
2	No	15.22%	7

Question 3:

We then asked, 'If you do not attend your screening invitation then please tell us why, what are the barriers for you, being nervous, not being aware what happens during the screening, previous poor experience, worried about the results, cultural or religious values etc':

Responses were as follows:

“I had a previous very unpleasant experience where the nurse did not appreciate that I was uncomfortable. I said it hurt and she said, ‘it does not!!’ I never got an invitation again so presume she thought I was difficult”.

“I could not make appointment at a suitable time as I'm a full-time carer with no support”.

“I had my last cervical screening two weeks after my 60th birthday. I was told that I would be over 65 (by two weeks!) before the next one was due, so I would not get my final smear. I contested this at GP level, PCT level and NHS England only to be told a big fat NO. I was told that even if I did get my test done at my GP surgery, it would be rejected for testing”.

“I don't feel that it's very important. I feel that the facts and figures lie. I feel there is too much pressure put on women to attend”.

“I had bad experiences during my first three screenings”.

“I am going to be 47 in a few weeks’ time, and I have only ever had one smear test which is my choice. I know I am mad but the way I see it, it’s my body and I don’t want to have it done. When I did have a smear test, I found the whole thing uncomfortable and embarrassing which I know is silly as it can save my life. I would go for a smear test if I thought there was something wrong”.

“There’s embarrassment, its invasive, too many false positives. Nurses running late, difficult to get an appointment or to get through to the surgery. If you do get through, then the receptionists are often rude and unhelpful”.

“I have had one smear test when I was very young and found it extremely painful and distressing. I have avoided going ever since, though not doing so does scare me because I know how important it is. I have experienced trauma throughout my life which makes this kind of procedure extremely difficult for me, and I just cannot go through with it as it triggers me so badly”.

“I attend them now, but I have missed them in the past. I had to rebook because I felt uncomfortable and triggered”.

Question 4:

If you do attend your invitation, how easy or difficult is it to book an appointment at the GP surgery?				
Answer Choices			**Response Percent**	**Response Total**
1	Very easy		36.36%	16
2	Easy		29.55%	13
3	Neither easy nor difficult		11.36%	5
4	Difficult		13.64%	6
5	Very difficult		9.09%	4

Question 5:

We then asked, 'please tell us about your screening appointment experience, are you made to feel comfortable, is the process explained fully to you, do you feel able to ask questions or raise any concerns, do you feel supported during the appointment etc':

Responses were as follows:

"The last time I went I was put completely at ease. All it takes is a friendly nurse/doctor to welcome you in with a smile and a happy tone. You don't really need to have yourself on show, you are covered for the most part. As a large woman, I am nervous going to the doctor for anything, for fear of being told whatever is wrong with me is because of my weight, but this is one appointment where I'm just a woman".

"I was made to feel comfortable, and the nurse explained what she was doing throughout".

"It's easy, quick, does feel a bit uncomfortable but better safe than sorry".

"It's always very straight forward, explained clearly and help is made to make me feel relaxed - as much as you can!"

"I was able to have an appointment on a Saturday at my GP surgery. It was explained well not rushed".

“It’s horrible, uncomfortable and to be endured. I hate them but such is life. Please ensure you don’t call us people with wombs, it’s soul destroying! I am only responding because you said ‘women’!”

“I really struggle with my screening test due to finding the use of the speculum painful. It has been this way since my first screening many years ago, but the lovely GP who first attempted the procedure suggested I come back another time and prescribed me some mild diazepam tablets to take prior to my next appointment. This made such a difference; I was less tense, and I was able to have the screening successfully at the second appointment. Now, years later, when I get my invitation letter, I still always request a few tablets from my GP once I have booked it - though still uncomfortable, I can tolerate the procedure with the medication taking the edge off my anxiety. I always tell the clinician that I find the procedure uncomfortable and ask them to use the smallest speculum they can, and no one has ever questioned that. They have always been kind and there seems to be a sense of camaraderie almost between patient and clinician as no one really likes having this done! The clinicians I have had for this procedure have always happened to be women, and to me that makes a difference because I know they are likely to have been through it too. I think it is important for all patients having this procedure to feel empowered to tell their clinician if they are nervous or find it painful etc. but not everyone knows that it is ok to speak up - if that kind GP had not supported me at the very beginning, I don’t know if I would have felt comfortable to speak up next time. I also would have had no idea that it was possible to have a very mild dose of diazepam to help get through it”.

“It was quick and easy, but the nurse ripped my vagina with the speculum, so I was in pain for a few days after. No lubricant was put or offered to go on the speculum which made it uncomfortable, but this wouldn’t put me off going again”.

“I was made to feel relaxed, comfortable - the process was explained to me although I've had many cervical screening appointments. I definitely felt I could ask questions and felt very supported. I have had horrendous cervical screening appointments in the past when I lived in a London Borough so to see the opposite approach is reassuring and is not a one off with my surgery - the nursing team are very supportive”.

“The whole experience is awkward and unpleasant, and being told to open up my legs while laying down only adds to my tension and makes the experience unpleasant. I had to be referred to the hospital last time and that was much more comfortable than the doctors, I could put my feet in stirrups and had a hospital sheet over the bottom part of me. I’m not a shy person but feeling completely naked down there and exposed is not nice when at the doctors”.

“It was flawless, all information was given in a kind manner, the procedure itself is extremely unpleasant but I always find the women are very understanding and very professional and considerate”.

“A lovely practitioner made me feel very relaxed and comfortable. She explained everything clearly and went through a few questions about my medical history. She discovered that my Mirena coil needed removing and did this at the same time. She was very calming and professional and chatted to me the whole way through which really helped. She took her cues from me and acted upon them”.

“The only issue I found was being a full-time worker and most places not doing late evening appointments. It isn’t nice using annual leave for a smear and not nice having to take a day of leave. However, in my instance it was worth it as the result was abnormal”.

“Last time I had to make a complaint to the surgery. The nurse taking my smear was very rude and unprofessional. I have had Cin 1 and 2 cells and a Letz procedure, so I am very cautious having my smears now and I was made to feel a fool at 40 years old. This experience would put many people off”.

“Although trying to book an appointment through my GP is difficult, on the day the process is well explained although the nurses can appear robotic at times. They are also very prone to running very late which adds to the stress of attending”.

“A while back I had an abnormal result which was concerning. The process of 'watch and wait' was just worrying, so I was relieved with a second smear from a Marie Stopes clinic which came back normal, which was reassuring. I paid for this which I would rather not have done on principle, but it was actually worthwhile for the peace of mind given”.

“The nurses are always friendly and explain each step to make me feel at ease, any questions I ask, they are happy to answer”.

“I am always supported during the appointment and yes, the process is explained to me. Although I have been having them for many years”.

“All was OK. The nurse was lovely, very friendly. It was over before it started really!”

“The nurse was very friendly. She explained everything thoroughly”.

“I've never had a problem with my screening appointment. The nurses have always been very helpful, have explained everything and put me at my ease. I don't feel there is anything that needs to be improved”.

“It’s easy, not too embarrassing, and the nurse is always very friendly and helpful”.

“I have always felt supported, and the staff are friendly and helpful”.

“The screening appointment is totally fine - no issues”.

“It's quick, painless and not embarrassing”.

“The process was not explained at all, it was rushed, and I was made to feel silly when I complained it was uncomfortable”.

“When I did have my one smear test all them years ago the nurse was nice and did her best to make me feel comfortable”.

“The appointment is fine, and explanations are clear, but it is unpleasant nonetheless”.

“The surgery's lines are always busy, often with half hour wait. Booking online would be a much better option. The appointment itself is always uncomfortable, I have never not experienced pain during and after. Surely something can be done to mitigate the pain”.

“I have always been made to feel comfortable and supported throughout my appointments”.

“I have to say I am almost 40, have had two children and still find my screening appointment absolutely horrific. I've had one good experience that didn't hurt. ONE! The last one was painful and so awkwardly uncomfortable (I'm upset before I even lay down) I'm seriously considering whether I will go to the next one when I'm called. I always wonder why it's such an awful experience (I'm never made to feel comfortable) and painful when I know it doesn't have to be because of that one time it didn't hurt”.

“I have great issue with the curtain being pulled around and sometimes the nurse leaving the room which obviously means the door isn't secure, also being given blue paper to cover your lower half and being told to relax and leave your legs wide open when you have both physical and emotional trauma. Your instinct is to tense up and cover up”.

“I was made to feel very comfortable, and the procedure explained”.

“The last time I attempted to have the procedure, I became distressed when on the bed. The nurse kept pushing the speculum in and it was really hurting, but she said she couldn't get it far up enough. I asked her to stop so that I could sit up and try to calm myself. She stood in front of me with folded arms and said, 'For goodness’s sake, what's wrong with you, have you been raped or something?' I had to get off the bed and leave, I cried all the way home”.

“I am lucky that I have only had positive experiences with my cervical smears. The nurse has worked at my GP surgery for over 20 years and has always done mine kindly and gently”.

“Several years ago, when living in Harlow, I had a couple of bad experiences when attending my smear test. On one occasion, I was called for a colposcopy due to my sample showing some abnormalities and was advised by my doctor that this meant I had cancer, which of course was not the case. This was especially distressing as I was in my early 20s and had only just left home and moved away from my family so had no support. On another occasion, the person performing the test experienced some problems with the instruments and left me on the table, with them still incorrectly inserted, whilst she went to fetch a colleague. I ended up surrounded by three people whilst in this position, which I found extremely degrading and distressing”.

“I often ‘almost don’t’ attend my smear appointments. There seems to be limited awareness of trauma-informed practice, particularly for women (how many - is it 1 in 4 now?) who have suffered sexual assault, rape, and/or domestic abuse. Laying in ‘smear position’ with your skirt pulled up, or trousers off for an intrusive procedure (although vital) is a triggering situation and can easily trigger panic, anxiety and fear. This is a hard thing for a person to ‘tell’ even a very nice female nurse. In addition, often people don’t want their past trauma on their medical notes so there’s an added conflict there. Afterwards, the same feelings as those from the original traumatising experience can re-surface. It’s exactly the same with dentists. My feeling should be that there are ‘trauma-informed appointment slots’ where no questions are asked, but the medical professional has had trauma-informed training and is fully aware of the potential effects of the cervical screening procedure. I think many women would then feel safer and attend their smear. Also, to underline that they can bring a trusted friend along with them who will be

welcomed to sit 'head end' and soothe the patient and then be some support for them afterwards. I do attend, but every time, when I'm driving home, I'm crying and shaking".

"I had one where I was told after having it done it was early even though they had sent the letter. I was three days early and the system said it wouldn't be checked because of being early and I would need to come back the following week. Even the nurse agreed it was ridiculous and phoned the technician, but they said the system would reject it. So, I rebooked".

"I was made to feel very comfortable. The nurse explained what was happening and I felt very comfortable".

Demographic questions:

Please tell us your age			
Answer Choices		**Response Percent**	**Response Total**
1	18 - 24 years	0.00%	0
2	25 - 49 years	63.83%	30
3	50 - 64 years	34.04%	16
4	65 to 79 years	2.13%	1
5	80+ years	0.00%	0
6	Prefer not to say	0.00%	0

Please tell us your gender			
Answer Choices		**Response Percent**	**Response Total**
1	Woman	97.87%	46
2	Man	0.00%	0
3	Non-binary	0.00%	0
4	Prefer not to say	0.00%	0
5	Prefer to self describe:	2.13%	1

Is your gender identity the same as your sex recorded at birth?

	Answer Choices	Response Percent	Response Total
1	Yes	100.00%	47
2	No	0.00%	0
3	Prefer not to say	0.00%	0

Please tell us which sexual orientation you identify with

	Answer Choices	Response Percent	Response Total
1	Asexual	0.00%	0
2	Bisexual	6.38%	3
3	Gay man	0.00%	0
4	Heterosexual/straight	87.23%	41
5	Lesbian/Gay woman	0.00%	0
6	Pansexual	0.00%	0
7	Prefer not to say	0.00%	0
8	Prefer to self describe:	6.38%	3

Pregnancy and maternity

	Answer Choices	Response Percent	Response Total
1	This question does not apply to me	91.11%	41
2	I am currently pregnant	2.22%	1
3	I am currently breast-feeding	4.44%	2
4	I have given birth in the last 26 weeks	0.00%	0
5	I prefer not to say	2.22%	1

Please select your ethnicity				
Answer Choices			**Response Percent**	**Response Total**
1	Arab		0.00%	0
2	Asian/Asian British: Bangladeshi		0.00%	0
3	Asian/Asian British: Chinese		0.00%	0
4	Asian/Asian British: Indian		0.00%	0
5	Asian/Asian British: Pakistani		0.00%	0
6	Asian/Asian British: Any other Asian/Asian British background		0.00%	0
7	Black/Black British: African		2.13%	1
8	Black/Black British: Caribbean		0.00%	0
9	Black/Black British: Any other Black/Black British background		0.00%	0
10	Mixed/multiple ethnic groups: Asian and White		0.00%	0
11	Mixed/multiple ethnic groups: Black African and White		0.00%	0
12	Mixed/multiple ethnic groups: Black Caribbean and White		0.00%	0
13	Mixed/multiple ethnic groups: Any other Mixed/Multiple ethnic group background		0.00%	0
14	White: British/English/Northern Irish/Scottish/Welsh		76.60%	36
15	White: Irish		2.13%	1
16	White: Gypsy, Traveller or Irish Traveller		0.00%	0
17	White: Roma		0.00%	0
18	White: Any other White background		14.89%	7

Please select your ethnicity				
19	Prefer not to say		4.26%	2
20	Other (please specify):		0.00%	0

Do you consider yourself to be a carer?			
Answer Choices		**Response Percent**	**Response Total**
1	Yes	15.56%	7
2	No	80.00%	36
3	Prefer not to say	4.44%	2

Please select any of the following that apply to you:			
Answer Choices		**Response Percent**	**Response Total**
1	I have a disability	4.26%	2
2	I have a long term health condition	17.02%	8
3	I am a carer	10.64%	5
4	None of the above	63.83%	30
5	I prefer not to say	4.26%	2

2.3 The Interviews

Individual interviews were conducted to collect personal stories. All participants gave their consent to have their interviews recorded. Participants were willing for their experiences to be shared within this report, however, to ensure their anonymity and confidentiality of information they provided, all names used are pseudonyms to protect identities.

Maz:

"I have only had one good experience of cervical screening. I always attend but I am very reluctant, and it is very painful. My cervix is in an awkward position-far back and this causes issues when I am having the smear test done".

Her last test was done by a nurse, and she said it was the first time it had not hurt. Maz queries why all nurses cannot complete the test in a pain free way? And what did that particular nurse do which was different?

She recalled that there were good bedside manners from the nurse. Maz can get very worked up and anxious. In the past there has been no time taken to reassure her.

She puts her fists under her pelvis to lift it up, which she finds much easier.

Maz said she feels embarrassed about being upset as well as the situation itself.

Meena:

Meena talked about how difficult it can be to make the appointment in the first place:

"Getting an appointment is a nightmare by either trying to book online as they are very slow in responding or if you dial in, it takes forever to get through and I don't like making appointments like that face to face in a crowded reception area. The option of weekend appointments would be helpful. I have a health assessment every two years as part of my health insurance through my employer and this includes a smear test".

I asked Meena what differences she felt there were between having a test done privately and at the GP surgery. "I think that having it done privately (although I can't get a Saturday appointment), feels a lot less rushed and you are treated more like a person rather than a number in a queue. The room also feels more relaxed, and they use stirrups which I find more comfortable than bending my legs right back".

Meena then talked about the differences between her first smear tests and her stepdaughter who has recently had a letter for her first one. "My stepdaughter got her first letter a couple of months back and there was a leaflet in the envelope explaining how it was done and what they were doing. My first letter when I was 20 was just a rough piece

of computer-generated letter. I think its improved but there is still a long way to go in stating that this test is optional, I feel that as women we are pressurized into getting this done both by our GPs and these days on social media too. My first two smears that I had in 1994 when I was 20 and again in 1997 at 23 were both done by male doctors with a female nurse in the room, and that would never happen now. I think it's a very personal thing to have done and something I have never really felt comfortable with."

Mandy:

Mandy had a very poor first experience:

"When I was 16 back in 1989, I went to the local family planning clinic and started on the pill but was only given three months' supply. When I went back for a repeat prescription I was told there and then that all women on the pill had to have a cervical smear and that I would be having one there and then or I wouldn't be able have the pill. The procedure wasn't explained at all apart from being told to remove my lower underwear and place my feet in the stirrups and it was done by a male doctor with a female nurse in the room and I have never felt more embarrassed, and it really hurt. Forward to 1991 and I was away at university. I registered with a local GP and when I went to get the pill from them was told my smear was overdue and they wouldn't accept me until I had had a smear. This was done a couple of weeks later by a female doctor with a female nurse present and this time I had to lay on a couch with no stirrups and also my breasts checked for lumps. Thankfully I was given a gown to wear but I wasn't expecting the breast exam.

By 1994 I had left university and moved again. Registering with a GP was easy and after a 6-month pill check once again, I was told my smear was urgently overdue and to make an appointment to see the nurse urgently. This I did and this time there were stirrups, but I had to undress totally with no gown for a smear and breast check. This time I said I wasn't happy at being screened and I was told in no uncertain terms that ALL women HAVE to have these tests.

I then got married and had three children and after baby number three at the age of 36, at my six-week postpartum check I was once again told that I needed a smear urgently and they would do it there and then. I still hadn't properly recovered from giving birth a few weeks before and the pain was off the scale. Thankfully shortly after that my husband had a vasectomy, so I didn't need contraceptives and despite immense pressure from GPs, nurses, and even receptionists I refuse to have this test.

The thing I can't get over is why some surgeries insist on women laying on a bed with stirrups which I find humiliating while others don't. When I asked one of the nurses why they use this type of bed with stirrups I was told it's because it makes taking the smear easier! For whom??"

Sue:

"I have only ever had the one cervical screening test and that was back in 2011, it wasn't a pleasant experience. This is the first time I have really talked about it. Like everyone else I got a letter inviting me to cervical screening six months before I was 25. I tried calling

my surgery to book an appointment and the phone rang and rang, no answer so I gave up. Eventually one of the staff called me to ask why I hadn't booked an appointment so I tried to book and there were no appointments later in the afternoon or early evening so I couldn't attend, cue a stroppy receptionist who was making out to me that it was my fault that I was a non-attender.

I then got a job where I get private medical insurance, I needed some jabs for a trip abroad so I booked in to get them done by a travel clinic at my local private hospital and the lady on the phone said I also qualify for a private 30 minute well woman check which included a cervical smear, would I like to book. I thought great and I was able to go on a Saturday morning. The female nurse who called me in was quite grumpy and a lot older than me, I couldn't get a rapport going with her. She asked a lot about my medical history and made me undress down to my underwear and I was weighed, blood pressure take, BMI and height measured. She then asked me to go being the screen and remove my underwear as she was going to do a breast examination followed by the smear and then a pelvic exam. I wasn't expecting this, and I felt very uncomfortable about it, I was expecting to take my top off and back on again for boobs, and then bottoms off for the smear. It was pretty embarrassing laying on the couch with my feet in the stirrups totally naked. The smear itself was incredibly uncomfortable, I said it was hurting but she said if she didn't do it there and then I would have to come back another day and get it done and not to be silly and just relax, which was all well and good, but she wasn't the one laying down and having a foreign object inserted into her vagina.

I have never been back since even though my GP has mentioned it to me numerous times over the years. These days I buy an off the shelf HPV test that I do at home and if it ever comes back positive, I will then see my GP. Even the receptionists have given me grief over my nonattendance, a receptionist once told me it's nothing to be embarrassed about as ‘her’ nurses see women's vaginas every day and it's nothing to be embarrassed about. That’s not the point”.

Yumi:

“Well, obviously they're necessary and that's the reason I go, but they have always been extremely uncomfortable and painful. I've regularly experienced bleeding afterwards, which has never been pleasant. So basically, that's my overall experience. Again, I'll regularly go whenever invited, but I understand that some people, if they had to experience that pain, they might not attend the following time. The staff are always friendly. They're always polite, professionals”.

Yumi went on to talk about the process of making an appointment: “It is a nightmare. I guess that those surgeries at the moment are extremely busy, so it is really hard to actually speak to someone and once you have to speak to someone, I guess that they do have to ask you sort of why you're booking an appointment, but it seems rather intrusive if a receptionist is asking you those kinds of questions. I would much rather be able to book it online”.

Zena:

“I went in for a cervical screening and this is one of the worst experiences I have had. I requested the smallest speculum as previous experiences with the larger ones had left me traumatised. The nurse was argumentative and dismissive of my concerns. I had to really assert my case before she relented. No lubrication was used and to add to the discomfort she seemed inexperienced and had multiple attempts inserting the speculum until finally after some verbal directions from myself she managed to insert it and carryout the screening. It was another traumatic experience to add to my ever-growing list. I am very worried about my next cervical screening!”

Jennifer:

“My first one was around 14 years ago. I went to the surgery and the first one I had was not a great experience at all. No effort was made to explain what was going to happen and this was my first experience of cervical screening. It was just like, well, you must know what's going on, we'll just carry on kind of thing. And it was really, really uncomfortable. They made no effort to make me feel more comfortable. I think it got to the stage where she couldn't find my cervix and just kept going, ‘well, you must have one’, she said, and I was like, ‘yeah, I must have’. She spent ages trying to find it then she said ‘No, no, I can't find it.’ I think she even had to go out and get somebody else to come in. Which increased my stress levels even more because it was like, oh my God, what's wrong with me? What's going on? Why have I got somebody else in the room now? This is really, really not great for me. Anyway, they eventually found it and said it faces the wrong way, which makes it more difficult to find, but not impossible. Oh brilliant. Anyway, then they did the actual smear, and it was like oh my God, this is really uncomfortable. And I got home and was like if I have to go through those every three years, I really don't want to.

Three years passed and my next letter came, and I was like, no, I'm just gonna ignore that. Just ignore it. For a while. And then they sent another one. I ignored that as well. The story picks up again when I was in mental health hospital, I was there for seven months and there was a physical health nurse who was particularly into Women's Health at the time. And she was asking patients, ‘have you checked your breasts? Have you had your cervical smear?’ Have you done all that kind of stuff and it came to this little smear thing and I was like, no, I've kind of just avoided it and. She said you can have it done here. I can do it for you, and you don't have to go anywhere, so I was like oh God, ok, I will have it done because I know I have to have it done and it's a sensible thing to do. But she also had the same problem, that she couldn't find my cervix. And I went through the process again. She was a lot more trauma informed and explained everything, showed me the stuff beforehand and kind of said, you know, ‘we can use the smaller speculum’. You know, you just need to chill out and it will just be you tell me to stop at any point, you know, all that kind of stuff.

So, it's a much more pleasant experience in terms of being comfortable around the situation, but the actual trying to get it done again was really painful and just not good at all. In the end, she said ‘I don't want to put you through any more stress’. She referred me to a hospital consultant who specialised in doing smear tests on people with difficult

cervixes. She was so lovely and explained everything to me, showed me the stuff they were going to use, gave me time to ask questions etc. I don't know what happened, but I froze after the test and was not able to communicate as I had totally dissociated but all the staff were so lovely and just gave me time to come round. I have all my smear tests done at the hospital; I don't go through the GP. Seeing the same consultant who knows me and gives me time makes such a difference, she always puts me at the end of her clinic so if I need more time then I am not stressed out by thinking I am taking too much time and making others late for their appointments. Without the help from the nurse in the mental health hospital, I wouldn't have attended any screening appointments".

Lea:

"So, my story is that I had a cervical smear test two weeks after my 60th birthday. That was at the beginning of June 2017. Shortly after, on the 3rd of July, the same year I received a letter telling me that I had just had my last cervical cancer smear because women are not called after their 65th birthday, meaning that my next smear would've been in June 2022, two weeks after my 65th birthday. So effectively I missed it by two weeks.

I phoned my GP, and he said 'no, you won't be eligible', but I did wish to challenge it. And he said I was quite within my rights to do that as I was only two weeks over. I was trying to be proactive about my health. And I had had recalls on previous smear tests, so that was something I'd always kept up to date with the smear test. There's a family history. My mother, I don't know whether cervical cancer and ovarian cancer are linked, but five years before that date she died of ovarian cancer. And my daughter also had had pre-cancerous cells couple of years before that. So, I thought this is something I need to be on top of. Normally, I just kind of accept, 'oh, well I'm not going to get anymore and that's it.' But it was something I decided to try and sort out.

I was told to refer my query to my primary care trust which I did by email. And I was told, 'No flexibility on dates. That's it. You're going to be over 65, go away.' I was told by the PCT to refer my query to NHS England, which I did, and I've tried to find the email on my system, but I cannot find it. It's so annoying. And I was even given the necessary contact information to contact the NHS. So, I had the name and everything and I did get a reply to that, probably exactly the same information now. So, I went back to GP for this information who told me, interestingly that she could do a smear test, but it would be rejected for testing because I was over 65. That was their thing.

I mean, there is a sort of a happy ending to this story, fortunately for me, or unfortunately depending on the way you view it, because I'd had a pessary ring fitted for a prolapsed bladder and I kept getting infections from the pessary ring, culminating in a visit to the doctor. And as a result of that, she actually did a smear test, and I was referred to Gynaecology and I had a lot of tests. And it was put down to the fact that it was a severe infection from the ring. My body was rejecting it. So, I did get the smear test, but not in the way I'd intended.

So, my point, I suppose it seems petty to me to have been refused my request because of such a short margin of being on the wrong side of 65, I also had a family history of problems in that area.

I was trying to be proactive, and I felt like I was kind of banging my head against a brick wall. That's my story".

2.4 Examples of screening projects/alternative methods:

As part of this project I spoke to Lucy Ainsley, Project Manager at the Very Important Invitation Project based in Suffolk. They work to address the barriers to cervical screening and support patients. The project is a co-production between Suffolk GP+, Public Health bodies, local charities, women and people in the community to promote accessible cervical screening https://suffolkfed.org.uk/healthcare-services/cervical-screening/

The project is currently in its third year and is funded by the ICB. They work with GP surgeries to help improve the environment within the clinical space to make it more comfortable for patients, they also look at language used by staff and deliver training to raise awareness and improve people's experiences. Elements of the project are:

- Working to raise attendance/develop relationships with various seldom heard groups - severe mental illness, learning disabilities, travellers, non-binary, transgender etc.
- Looked at use of language. Women and people with a cervix, not just using the word 'woman'.
- Colours on promotional material; yellow and black is easier for people with sight issues to see. No pink!
- They worked with The Portland Hospital-surgeries can have a small card at reception which shows they are trans friendly.
- Being mindful of people's different situations and experiences.
- Changing mindset in frontline staff- such as 'it's always been done this way' etc. Educate older members of the staff team.
- NHS template form – this is completed before the appointment so any issues/triggers/previous experiences etc can be identified and acknowledged. It covers trauma etc - they have changed some of the wording.
- Minium of a 15-minute appointment, so time taken to ask a range of questions, and give a more holistic approach. Questions regarding sex life, periods etc, gives patients time to talk.
- Appropriate room set up, couches in the right positions for the patient and staff member. Working with practice manager to achieve a better environment. Not having the bed facing the door, makes patients feels more secure and comfortable. A three-month review is carried out with the surgery to monitor progress and evaluate.
- Using the correct lube - reducing the number of rejected samples.
- Translated material - working with local charities and organisations to see what languages are needed.
- Social media campaigns.
- Build relationships with the travelling community - monthly visits to sites to see what the women need and how they want it done.
- They are able to carry out stand-alone clinics - extended access service.

- Worked with Suffolk Rape Crisis and will deliver two clinics for people who have suffered rape/sexual assault.

Self-testing

One interviewee talked about choosing to do her cervical test at home, and this was not something I had heard about before, so I wanted to find out more information. I found that patients can buy an HPV test from a pharmacy for around £50, complete at home and then send off for the results.

Buy Home HPV Test Kits Online | Superdrug Online Doctor

What Is A Home HPV Test? | LloydsPharmacy Online Doctor UK

It is understandable that some people may find this a much easier process to cope with than attending a surgery, it takes away the stress of having to make an appointment and gives them total control over how and when they carry out the test. I talked to some health professionals about this option and they had concerns around how reliable the test was and they would want to see more research before considering it as an option. It is an option which should be explored in more detail, it is important for people to have a choice around how these screening tests are carried out and that they feel more in control in this situation.

There was a YouScreen (Kings College London) trial in some London boroughs in 2021 where women were offered home testing kits:

Cancer: Women to trial 'do-it-at-home' kits for NHS - BBC News

https://www.england.nhs.uk/2021/02/nhs-gives-women-hpv-home-testing-kits-to-cut-cancer-deaths/

I was unable to find the outcome of that trail but there are other findings from Kings College London regarding cervical self-screening:

https://kclpure.kcl.ac.uk/portal/en/publications/offering-self-sampling-to-cervical-screening-non-attenders-in-pri

'Offering non-speculum clinician-sampling and self-sampling substantially increases uptake in older women with lapsed screening attendance. Non-speculum clinician sampling appeals to women who dislike the speculum but prefer a clinician to take their sample and who lack confidence in self-sampling. **Providing a choice of screening modality may be important for optimising cervical screening uptake.'** Non-speculum sampling approaches for cervical screening in older women: randomised controlled trial — King's College London (kcl.ac.uk)

Denmark and Australia are two countries which offer self-sampling tests. These tests are still carried out in a clinical setting but with the patient doing the actual test themselves. This is the video explaining the procedure from Australia:

https://www.health.gov.au/self-collection-for-the-cervical-screening-test

National Cervical Screening Program monitoring report 2022, Summary - Australian Institute of Health and Welfare (aihw.gov.au)

Self-collection

Participants who self-collect their cervical screening sample and whose primary screening HPV test detects oncogenic HPV types need to return to a practitioner for an LBC (liquid-based cytology test) or attend for a colposcopy, depending on the oncogenic HPV types detected.

In 2021, of the 327 participants aged 30–74 whose self-collected primary screening HPV test detected an oncogenic HPV type other than 16 or 18, 60% had an LBC within 6 months.

In 2021, of the 130 participants aged 30–74 whose self-collected primary screening HPV test detected oncogenic HPV type 16 or 18, 69% had a colposcopy within 6 months.

Cervical Screening and HPV Self-Sampling in Denmark – Cancer Prevention Group Blog (kcl.ac.uk)

HPV self-sampling instead of clinician-collected screening samples?

'There is no doubt that HPV self-sampling can and should be an option for cervical screening. The benefits are too plentiful to ignore. In addition to the autonomy it brings for women, self-sampling offers equity and a means to address clinician-patient working pressures in primary healthcare. Imagine if, say, a third of all women screened by clinician-collected samples instead took a sample by themselves. The number of clinical consultations freed up for other purposes would be substantial. If this can be achieved without compromising screening quality, everyone stands to benefit: women, overworked healthcare professionals, the health system, and society itself. On the other hand, do we want self-sampling to fully replace clinician-collected samples? At present, I personally think not. It is about choice and providing options.' **Jesper Bonde** 2023

It is important to look at other possible options to enable people to access the screening process. The current method has been used for a long time now and it doesn't work for all patients, having the option to do the test yourself in a clinical setting or at home could help to improve the uptake.

3.0 Key Findings and Recommendations

Almost 85% of the survey respondents attended their cervical screening appointment. This is very positive considering the general feeling is that the process is necessary but still an

unpleasant and difficult experience for many. ‘It’s horrible, uncomfortable and to be endured. Hate them but such is life.’

Cervical Screening Programme, England - 2021-2022 [NS] - NHS Digital

69.9% of eligible individuals aged 25 to 64 adequately screened.

A 0.3 percentage point decrease on the previous year, when coverage was 70.2%.
(Coverage assessed at 31 March 2022)

There was a wide range of feedback from the participants. The first step of making an appointment was difficult for many, as the time taken just to get through to the surgery was an issue and then trying to get an appointment which suited them was also a challenge. People who work full time or had caring responsibilities found it difficult or impossible to make an appointment that they could attend. ‘I could not make appointment at a suitable time as I'm a full-time carer with no support.’ Many people stated that being able to book this type of appointment online would make the process much easier. Pressure to attend appointments was also a factor in making respondents reluctant to attend, ‘Even the receptionists have given me grief over my non-attendance, a receptionist once told me it's nothing to be embarrassed about as "her" nurses see women's vaginas every day. That’s not the point.’

Many talked about historical experiences which were at times very traumatic and had an impact on their screening experiences and for some of them it led to delaying or not attending future invitations. Examples included, male doctors carrying out the procedure, not explaining the procedure/process, health professionals not listening to their patient- especially when stating they were in pain, being left on an examination couch while in a venerable position etc. These were all examples of poor practise/experiences which had an impact on the patient. ‘On another occasion, the person performing the test experienced some problems with the instruments and left me on the table, with them still incorrectly inserted, whilst she went to fetch a colleague. I ended up surrounded by three people whilst in this position, which I found extremely degrading and distressing.’

Trauma awareness must be recognised and be part of the cervical screening process to enable women who are survivors to access the same service as others. ‘I often ‘almost don’t’ attend my smear appointments. There seems to be limited awareness of trauma-informed practice, particularly for women (how many - is it 1 in 4 now?) who have suffered sexual assault, rape, and/or domestic abuse. Laying in ‘smear position’ with skirt pulled up, or trousers off for an intrusive procedure (although vital) is a triggering situation and can easily trigger panic, anxiety and fear. This is a hard thing for a person to ‘tell’ even a very nice female nurse. In addition, often people don’t want their past trauma on their medical notes so there’s an added conflict there. Afterwards, the same feelings as those from the original traumatising experience can re-surface.’

Language used by the health professional has to be appropriate in all situations, but especially around trauma, ‘The last time I attempted to have the procedure, I became distressed when on the bed. The nurse kept pushing the speculum in and it was really hurting, but she said she couldn't get it far up enough. I asked her to stop so that I could

sit up and try to calm myself. She stood in front of me with folded arms and said, 'For goodness's sake, what's wrong with you, have you been raped or something?' I had to get off the bed and leave, I cried all the way home.' A number of respondents stated that when they told the health professional that what they were doing was hurting, they were told it wasn't or to stop being silly and just relax. This is shocking behaviour and completely unacceptable. One respondent felt that the whole procedure was aimed at suiting the health professional and not her, 'The thing I can't get over is why some surgeries insist on women laying on a bed with stirrups which I find humiliating while others don't. When I asked one of the nurses why they use this type of bed with stirrups I was told it's because it makes taking the smear easier! For whom??'

Many respondents however did have positive experiences and recognised the kindness, respect and professionalism shown to them by health professionals, 'Flawless, all information given in a kind manner, the procedure itself is extremely unpleasant but I always find the women are very understanding and very professional and considerate.'

Recommendations:

- Making the appointment made easier - having the option to pre book appointments would be of benefit, as having to phone at 8am to attempt to make an appointment for a matter that doesn't necessarily have to be carried out that day is not an effective use of patient's/surgeries time. Having the option to book online should be explored.

- Trauma awareness - Training to raise awareness for all staff involved including receptionists as well as health professionals. 'My feeling is that there should be 'trauma-informed appointment slots' where no questions are asked, but the medical professional has had trauma-informed training and is fully aware of the potential effects of the cervical screening procedure. I think many women would then feel safer and attend their smear. Also, to underline that they can bring a trusted friend along with them who will be welcomed to sit 'head end' and soothe the patient and then be some support for them afterwards. I do attend, but every time, when I'm driving home, I'm crying and shaking'.

- Environment - making sure the clinical setting is as welcoming as it can be; where possible not having the bed facing the door, allowing women to be in a position that they find as comfortable as possible, having the option to use stirrups if required for them. But also factoring in that the health professional needs to be comfortable whilst they are carrying out the procedure. Using the correct lube so the patient is comfortable, and an adequate sample is taken.

- Taking the time - making the appointments slightly longer so a more holistic approach could be adopted, having the option to ask questions around general sexual and menstrual health. Checking to see if there is any previous trauma or negative past experiences that could impact the appointment. Giving the patient an opportunity to ask questions so they don't feel rushed or like a number instead of a person.

- Explanation and communication - explaining what is going to happen, allowing patients to see/feel the instruments being used if they want to, checking in with the patient during the procedure that they are as comfortable as they can be. Stopping if the patient is in pain or distress and allowing them time to calm down and continue or leave, it's their choice. Listen.

4.0 Conclusion

85% of people attending their cervical screening appointment following an invitation letter is a very positive number and above the national average. Many stated positive experiences and were happy with the process. This is a good outcome and a solid base to build upon.

There needs to be more work done regarding trauma awareness/training and the impact this has on an individual and their experience, not just for regular screening but across the healthcare system. Women must feel that they have a choice in where, how and when they decide to have a screening appointment. The one size fits all approach does not work in the current system, it requires a review and a rethink.

Looking at examples of good practice and how cervical screening is carried out in other ICB areas and countries can give suggestions/ideas on how to develop the programme.

Co production is vital part of the process of developing a programme that benefits as many people as possible. Building links and relationships with seldom heard communities will not just improve the uptake of cervical screening but also help to improve other health outcomes. Asking for lived experience can, at times, be a difficult process for both parties. It can be difficult to share one's own personal and sometimes traumatic stories and they can also be difficult to hear/read and process, but it is so important to hear those stories and for them to influence positive change.

Hertfordshire and West Essex Integrated Care System

NHS Hertfordshire and West Essex Integrated Care Board

Meeting:	*Meeting in public*	x☐	*Meeting in private (confidential)*	☐			
	HWE ICB Primary Care Board Meeting				**Meeting Date:**	**28th September 2023**	
Report Title:	**Cervical Screening experiences in west Essex.**				**Agenda Item:**	**11.2**	
Report Author(s):	Sara Poole-Information and Guidance Officer-Healthwatch Essex						
Report Signed off by:	Avni Shah, Director of Primary Care Transformation						
Purpose:	**Approval**	☐	**Decision**	☐	**Discussion**	☐	**Information** ☐
Report History:	N/A						

Executive Summary:

Healthwatch Essex has been commissioned by the Hertfordshire and West Essex Integrated Care System (ICS) Primary Care Workstream to undertake a series of engagement projects.

This report is focusing on-The Cervical Screening process-gathering feedback and lived experience.

Key Findings:

Accessing GP Services to make an appointment for screening.

- Having to phone at 8am to attempt to make an appointment and still not being successful when they do manage to get through.
- Difficulty in making an appointment which suits the patient, those who work and/or have caring commitments found it difficult to get an appointment at a suitable time. More evening/ weekend appointments are required.
- Poor attitude from some frontline staff, people said they were made to feel guilty if they hadn't attended a screening appointment when due.

Previous experiences:

- Many people stated that due to poor previous experiences, this made them reluctant to attend further appointments.
- Being made to feel like a number rather than a person and being rushed through the appointment were also factors in people not attending again.
- A positive first experience has a massive impact on that person attending future screenings. Historical poor experiences regarding male doctors, lack of communication regarding the procedure and not being listened to all had an effect on the chances of that person attending again.

Positive stories:

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- There were many positive stories where people were made to feel comfortable, and the procedure was carried out with care and respect.
- Time taken by staff to explain the procedure and allow time for questions was commented on as part of making the experience as positive as possible.
- Being treated with respect and kindness is vital.
- Good communication and listening skills are also vital to ensure a positive experience.

Trauma awareness:

- Those who had a history of trauma found it extremely difficult to attend appointments.
- Awareness of trauma and how it can affect someone before/during and after a screening appointment should be recognised and adjustments/extra support should be available for those patients.

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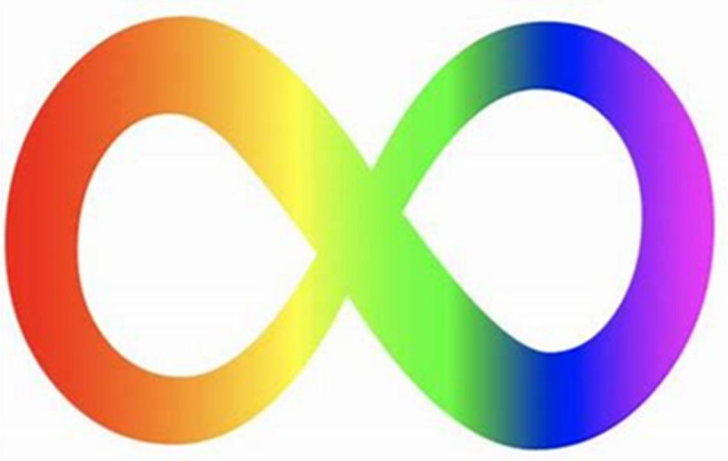
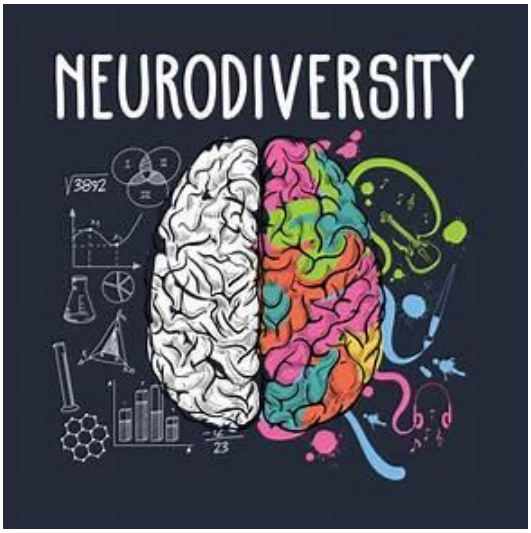
Impact Assessments (completed and attached):	***Equality Impact Assessment:***	
	Quality Impact Assessment:	
	Data Protection Impact Assessment:	
Strategic Objective(s) / ICS Primary Purposes supported by this report:	***Improving outcomes in population health and healthcare***	x☐
	Tackling inequalities in outcomes, experience and access	x☐
		☐
		☐
		☐
		☐

healthwatch Essex

Neurodiversity & Accessing Health and Care





Produced by Healthwatch Essex
Fergus Bird
Information & Guidance Officer
July - September 2023

Contents

1.0 Introduction

1.1 Healthwatch Essex

Healthwatch Essex is an independent charity which gathers and represents views about health and social care services in Essex. Our aim is to influence decision makers so that services are fit for purpose, effective and accessible, ultimately improving service user experience. We also provide an information service to help people access, understand, and navigate the health and social care system. One of the functions of a local Healthwatch under the Health and Social Care Act 2012, is the provision of an advice and information service to the public about accessing health and social care services and choice in relation to aspects of those services. This document was revised in July 2022 and the role of Healthwatch was further strengthen as a voice of the public with a role in ensuring lived experience was heard at the highest level.

The Healthwatch Essex Information and Guidance team are dedicated to capturing the health and social care experiences people in Essex are meeting daily. The team respond to enquiries relating to health and social care and are equipped through training, to offer specific information to the public or other professionals. The team are well placed to listen, reflect on and support people to share complex experiences such as the one's shared in this report.

1.2 Topic Background

Healthwatch Essex were approached by Hertfordshire and West Essex ICB to undertake a series of projects focussing on the lived experiences of people in the area in relation to their health, care and wellbeing. Two projects are selected per calendar quarter for in depth engagement, with the production of a report based on this engagement.

1.3 Acknowledgements

Healthwatch Essex would like to thank the hundreds of people who engaged with us, participated in this project, and completed the survey.

Our thanks are also made to those individuals who took the time to speak with us and share their personal stories.

We would also like to thank our many partners, contacts, and networks who worked with us to share the project and survey throughout all of West Essex and help generate such a strong level of interest and feedback.

1.4 Disclaimer

Please note that this report relates to findings and observations carried out on specific dates and times, representing the views of those who contributed anonymously during the engagement period. This report summarises themes from the responses collected and puts forward recommendations based on the experiences shared with Healthwatch Essex during this time.

2.0 Purpose

The purpose of this report is to take a closer look at the relationship between the NHS in West Essex and its neurodiverse population and their carers and families, particularly in regard to the provision of, and access to, GP services. It's designed to identify what's going well, what challenges need addressing, where there might be gaps, and where there are successes. The results and recommendations can in turn help develop the ICS strategy and deliver positive outcomes.

2.1 Engagement methods

Participants were contacted through the Healthwatch Essex website, an online survey, direct contacts via our extensive network, through local West Essex based Facebook groups, the Healthwatch Essex newsletters, our own Facebook page, Instagram account and Tik-Tok. Word of mouth also played an important role along with promotion of the project via our extensive networks.

Our partners, other organisations and working groups in West Essex, together with our volunteers and many individuals inside and outside of the NHS and ECC helped and supported our efforts to engage with and reach as many people throughout the area as possible.

They were engaged with in two ways:

A Survey
A survey was created to gain perspective and insight from Residents in West Essex who have had experience of living with Neurodiversity.

Interviews
Individual interviews were conducted to collect personal stories from members of the public. Interviews took place by telephone during August and September 2023 and all participants gave their consent to have their interviews recorded. Participants were willing for their experiences to be shared within this report, however, to ensure their anonymity and confidentiality of information they provided, all names used are pseudonyms to protect identities.

2.2 The Survey

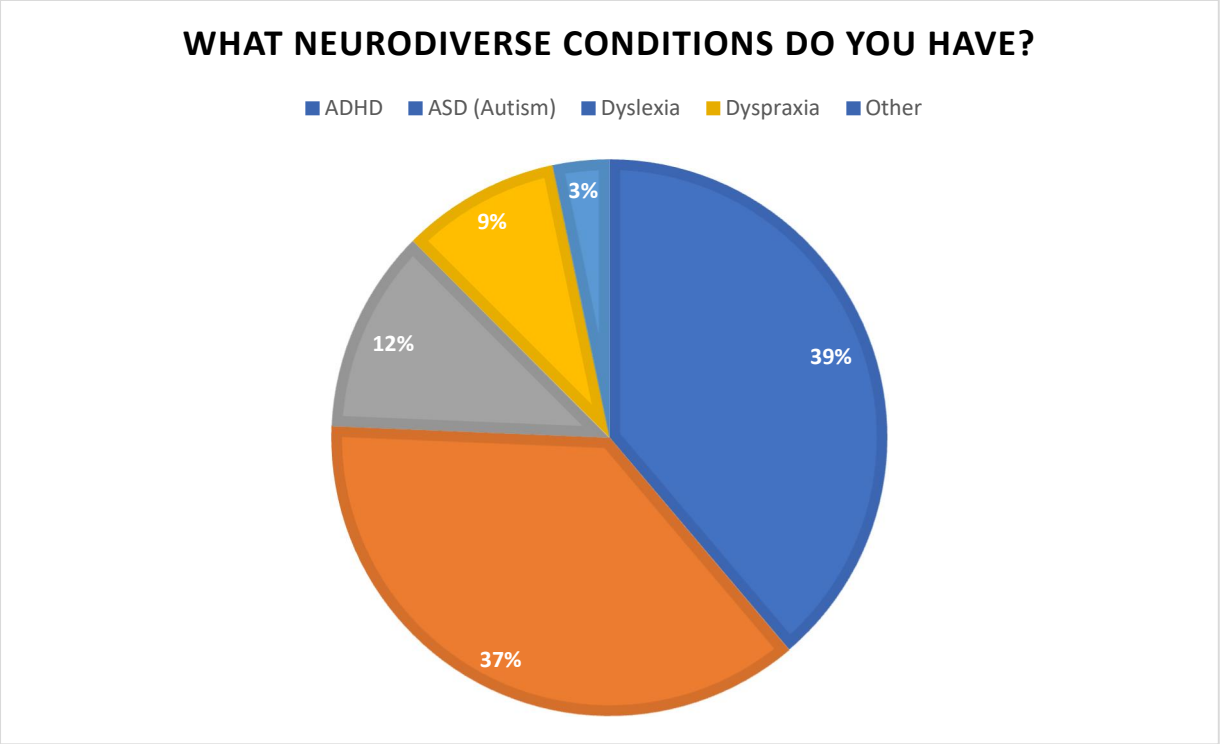
The survey consisted of nine core questions, mixing multiple choice questions and 'free text' information boxes enabling the participants to expand on their answers with their own lived experiences. There were an additional three demographic questions.

It was devised to encompass three main areas:

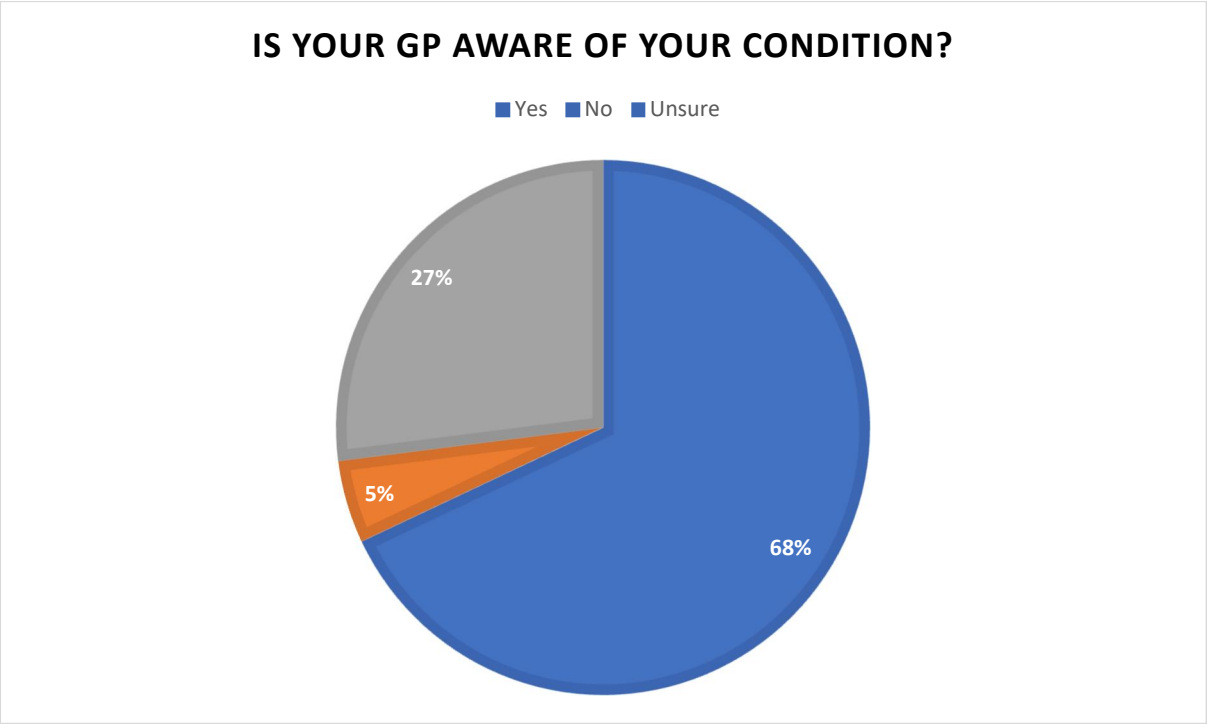
- Their GP relationship.
- Making an appointment.
- Visiting the surgery.

And crucially, it allowed their voices to be heard.

The survey was primarily in an online format but was also available to be printed off and filled out manually as required. The Information and Guidance Team at Healthwatch Essex were also available if the survey needed to be completed in any other format, such as over the telephone. The questions, and responses received, were as follows:



Nearly 50% of respondents selected multiple conditions. 'Other' included Dyscalculia, Dysgraphia and Tourette's Syndrome. It should be noted that Tourette's is often referred to as a neurodevelopmental condition, and not always considered a neurodiverse condition, but for the purposes of this survey we have included it. Almost as many participants identified as having ASD.



68% of respondents stated that their GP was aware of their condition, which is fairly high, but nonetheless leaves a significant number for whom the GP is not definitely aware of a condition which will directly impact upon their healthcare and wellbeing.

We then asked those whose GP is aware of their condition to tell us about their relationship:

We asked, 'How well does your GP understand you as a neurodiverse person?'

Here is a representative selection of responses:

'It's rare that I see my own GP and it's not something that comes up in discussion. I often feel embarrassed to disclose my condition due to the stigma attached to being a 30 something year old woman with ADHD. There is a common misconception/narrative/belief that it's some sort of trend, that everyone is jumping on the band wagon. For me it's a curse, and I feel I have to justify it to healthcare professionals or attempt to mask it, albeit poorly, to avoid judgement.'

'I see a different GP each time, sometimes locums, and I'm not sure that they look closely, or at all, at my notes before I go in. Communication is difficult as they don't make the time to talk and understand what's in my head. I don't think they have much training.'

'Not at all'

‘I have Tourette’s syndrome and mild learning difficulties; my current GP understands my condition very well and has been very helpful with being able to make early morning appointments for my annual health check’.

‘They don’t, at all, and aren’t interested in understanding. I have to refer to how children present to make them understand. I’ve had to point out you grow out of autism.’

‘I don't know, as I don't speak to the same GP every time and I am very good at masking. I most often speak with receptionists who are likely not aware of my diagnosis unless I'm specifically calling about it.’

‘Not very well it seems. I have to let them know before I talk, but the understanding is low’.

‘Some GPs are much better at being understanding, some are not. Sometimes they will make adjustments, and some will not give any time to process the information or expect an answer quickly. A lot of the time I feel very rushed meaning I don’t get the best out of my appointments’.

‘I don’t feel they do’.

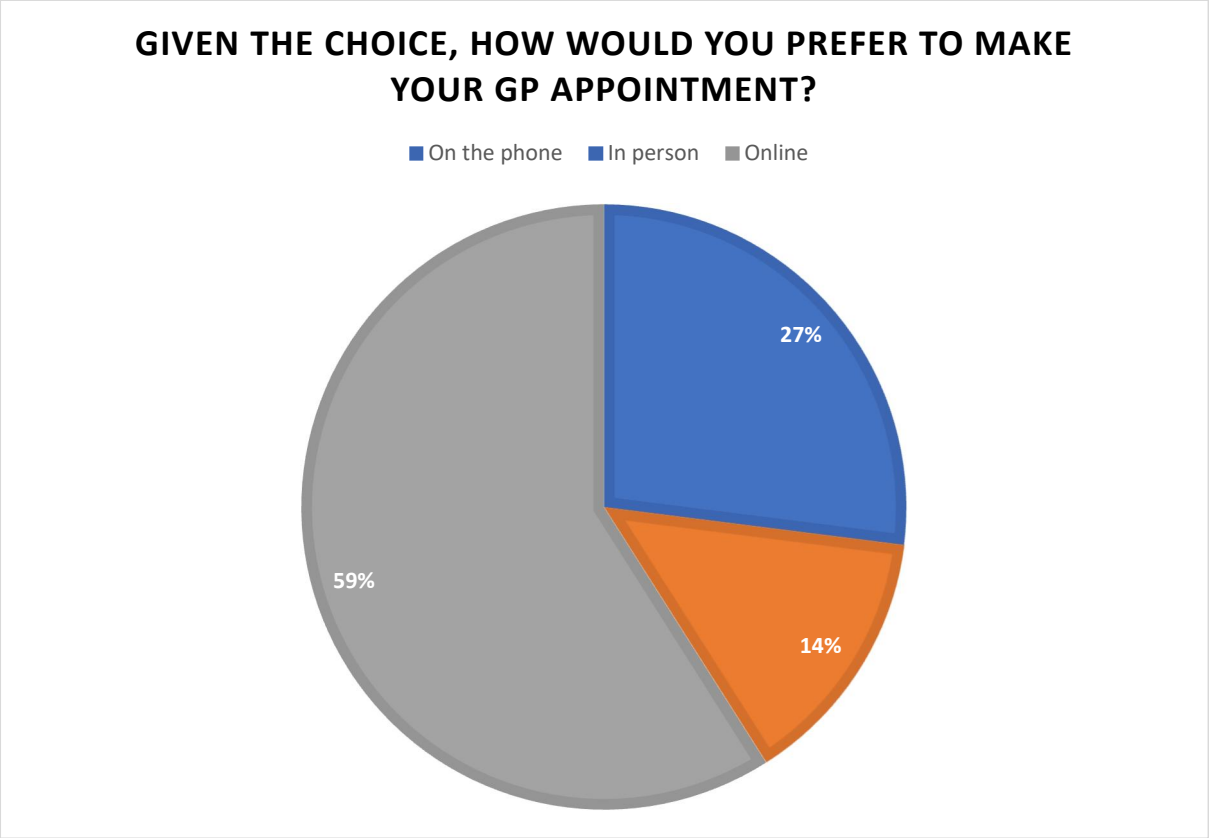
‘No idea’

‘There is no understanding or accommodation to the point where it is dismissive and gaslighting.’

‘I never see the same one twice so who knows’.

‘They are aware that I was diagnosed a little under two years ago as an adult. This was via a private assessment. My GP is in the process of referring me to move under NHS psychiatrist care. My GP has already taken on my medication. My GP is aware but often I have to see other GPs at the surgery who are not aware.’

‘Yes, I suffer from ADHD and yes, my doctor is very aware of it; in fact, I think my doctor knows more than me! Personally, I think I need to speak with a trained psychiatrist so I can talk about some of my problems etc.’



There is a very high preference for making appointments online from this cohort. Some of the reasons behind this emerge throughout the next question:

We then asked, 'What difficulties do you face when making an appointment to see your GP?'

A representative selection of responses follow:

'Having to make a phone call on the day or having to remember to phone back after a certain time. Making phone calls is very stressful for me.'

'I can't get through on phone and I can't get the doctor I like.'

'Lack of ability to make appointments online without calling.'

'I ask for a face-to-face appointment, and I never get one. I get frustrated as I find phone calls difficult sometimes.'

‘They don't allow for the combination of factors, the neurodiversity as well as whatever the reason for contacting them is.’

‘Having to call up at 8.30am and not being able to access a slightly longer appointment. You can’t book some appointments in advance so I will often forget to go back.’

‘It’s online only, so you are unable to query or change things and get told off if you ring. Medical requests are only at 8am or 2pm.’

‘Same as everyone, I wanted to see a particular GP. They work part time; they are very popular - I was given an appointment for a month's time’.

‘I am unable to make phone calls so need a carer or family member to do it for me as I suffer with severe anxiety’.

‘You cannot get through by telephone, the wait is too long. Even though I am on the Learning Disability Register I am not shown any priority or care. There are still no online appointments available or future appointments. You have to make an appointment on the day.’

‘Having to get online at 8am in the morning you want an appointment and if you are lucky enough to get one you just a phone call with a locum.’

‘I am terrible at remembering to call the doctors, especially considering it needs to be done at the right time or there's no hope of getting an appointment. I also feel bad for taking up time but that's a weird empathy/anxiety thing I don't think I can really explain. As it is generally easier for me to have a phone appointment, I end up in waiting mode when the rough time frame I've been given happens, so I stop being productive, something that isn't great considering I am 99% of the time at work.’

‘I work for the service and understand the challenges faced in primary care. People with ADHD are suffering inequalities due to their symptoms. Our thought and planning horizons differ dramatically compared to neurotypicals. We struggle to think weeks in advance, this means we are often too disorganised to book important appointments such as cervical screenings, health checks or medication reviews. We are more likely to procrastinate over a medical issue before approaching the doctor. This in itself can further delay seeking a diagnosis or assessment. And if we decide to contact the doctor, we need an appointment for that day or that week, to be told it’s a six week wait, we are likely to forget or struggle to make the appointment because it is not within our horizon. We are terribly forgetful and need multiple reminders, a ping an hour before the appointment would help so many ADHD

people. We also struggle with “waiting mode”, this means that an appointment midday or in the afternoon can lead to a total mental paralysis, where we will do nothing but clock watch until the appointment. Early appointments first thing would leave us to relax and enjoy the rest of the day. Many of us also have Sensory Processing Disorder, so telephone queue music and messages can feel physically painful.’

‘They only ring the phone a few times and if I miss the call, I have to make another appointment. Not getting through on the phone and being on hold is too overwhelming’.

‘Having to speak on the phone or online.’

‘Phoning in – the same as for everyone else.’

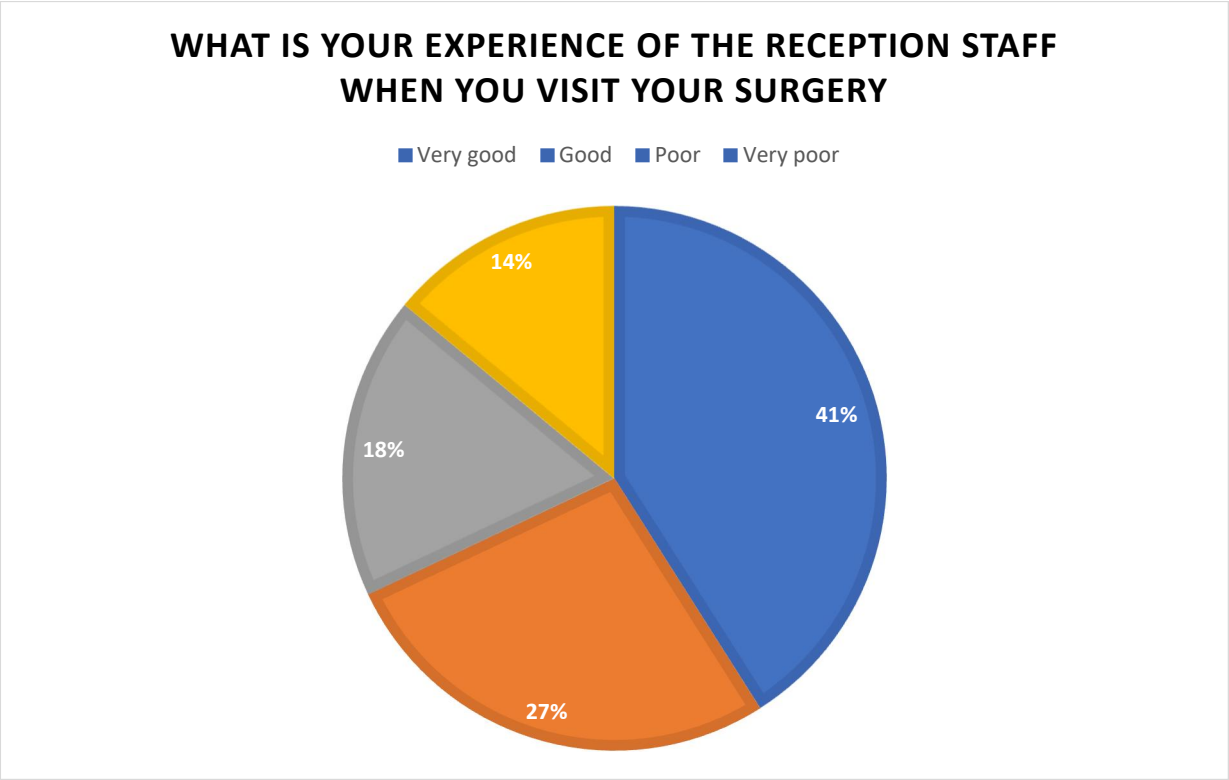
‘Long waiting times on the phone. I could be on hold for hours.’

‘When they send me from my usual surgery to their other one.’

‘I get agitated if people don’t listen properly, and trying to sort out repeat prescriptions is challenging.’

‘It's incredibly difficult and frustrating. Phoning is so difficult. It's so busy and then I get to the queue only for it to be full and told to call back later. I continually phone and have done for 45 minutes or more constantly in the past to try and get through. I regularly avoid calling due to the difficulties it causes me. It makes me feel very stressed, I pace around and often having waited in the queue if I have made it that far I end up hanging up because it has taken so long. It was better when I could use eConsult. To be able to use voice as well as typing to fill it in would be great. Unfortunately, my surgery stopped using eConsult. Screening questions on eConsult were helpful and included gambling which is very important.’

‘Getting face to face appointments is much more difficult since Covid19 hit us. And personally, I think a lot of people have given up on life, with the war etc.’



Comments added in relation to our question about participants experiences of GP reception services were as follows.

‘They have no understanding of "High functioning" and “masking”.’

‘It’s been good and bad. It depends how stressed the staff are. And it's all online now which can be frustrating for patients like me.’

‘They are friendly and helpful.’

‘There are a couple who are nice and very helpful but then some of them just don’t have any understanding at all. They can be really rude and don’t understand that what they are asking me to do, I can’t do. They asked me to fill out forms, but I was forced to explain in front of the whole waiting room why I can’t do it.’

‘They are unhelpful and ask too many questions.’

‘They are no help; they don’t explain the particular surgery’s procedures and they change what I have to do every time I need my medication changed.’

‘They have improved. Previously it always seemed to be a bother to request an appointment for myself or my children who also have challenging needs.’

‘They are always so unhappy to help and look at me strange when I say I am autistic, and they ask very in-depth questions.’

‘They have always been very helpful to me.’

‘Very professional, always considerate and kind but they always seem to be miles away.’

We then asked, ‘What adjustments could be made to improve your experience of visiting your surgery? Please consider the waiting area, forms & leaflets, appointment times, registration, choice of practitioner and anything else.’

We received the following responses.

‘Not being kept waiting too long in the crowded waiting room, updated on delays/number of people in front of me, and choice of practitioner is important.’

‘Nicer seating, good Wi-Fi and not having my name shouted out when they’re ready to see me.’

‘Online access and more understanding.’

‘Nothing is easy anymore. You have to jump through hoops to just get a referral or an appointment and the appointments are always rushed.’

‘This is already quite good but there should be more help and diagnosis / treatment for people who have ADHD and don't have the support or the finances to go private.’

‘Quiet space to wait in, and something to show doctors and receptionists what help I need. Easy read leaflets. Information in different formats, longer appointments if needed, support to fill out forms and a space to have a private conversation so you don’t feel humiliated having to explain about your neurodivergence in front of other patients. Staff to have more patience and compassion when you explain your difficulties and need support. On many occasions I have been moaned at by reception staff. A lot more understanding of someone’s needs is needed. Sometimes the processes don’t work but there is no flexibility to allow reasonable adjustments. To have someone who works across the GPs who have training in neurodiversity who can support at appointments should you need it. A text could be sent

after appointments with basic information about your appointment with instructions and what was said as sometimes it's very hard to remember.'

'Info on the practice website is wrong. I am only registered there as they advertised new patient health checks. This turned out to be false which has caused no end of problems, so no one is aware of my autism. Since the pandemic all waiting rooms are cold and unwelcoming no matter where you go. I was told the NHS has changed in September 2022, after going back and forth trying to get someone to explain blood tests, where was it advertised that absolutely everything had changed? There was no choice of practitioner. I've said I don't understand the doctors in the surgery, and I don't understand any of my diagnoses and why nobody seems to want to explain either. The NHS had the caring element removed in 2020 and it's very, very noticeable. I've been told my death isn't worth preventing and I can't work out if that's because of my autism diagnosis and having a poor clinical frailty score or DNR/DNACPR on my health file because of it. I'm currently waiting to die as I can't get any treatment for anything I've been diagnosed with- heart failure and a blood clotting disorder. I can't even get anyone to explain what it means for me. My health info comes from Google as the NHS is not accessible anymore.'

'A quiet area in the waiting room.'

'Choice of who to see. Continuity. Being seen on time. More privacy at reception.'

'To be able to make an appointment in advance, to actually go to the surgery and see a real person.'

'It would be really great if I could be in a space where I don't have to worry about not hearing the beep/my name called because of how invested I get in whatever I'm doing to pass the time or if I'm listening to music. I also have some issues with auditory processing so I might not respond to my name, especially if the room is loud.'

'For people with ADHD, first thing in the morning appointments will help tremendously to avoid "waiting mode". It would be amazing to have the opportunity to wait outside or in a quiet area without the noise, lights and people. I think everyone could benefit from inclusion training, to understand the neurodiverse conditions and what our needs could be, how we may communicate or come across, it's exhausting having to mask.'

'To stick to appointment times and not make us wait. Online communication only. Fast communication. To stick to only one doctor and not see different ones.'

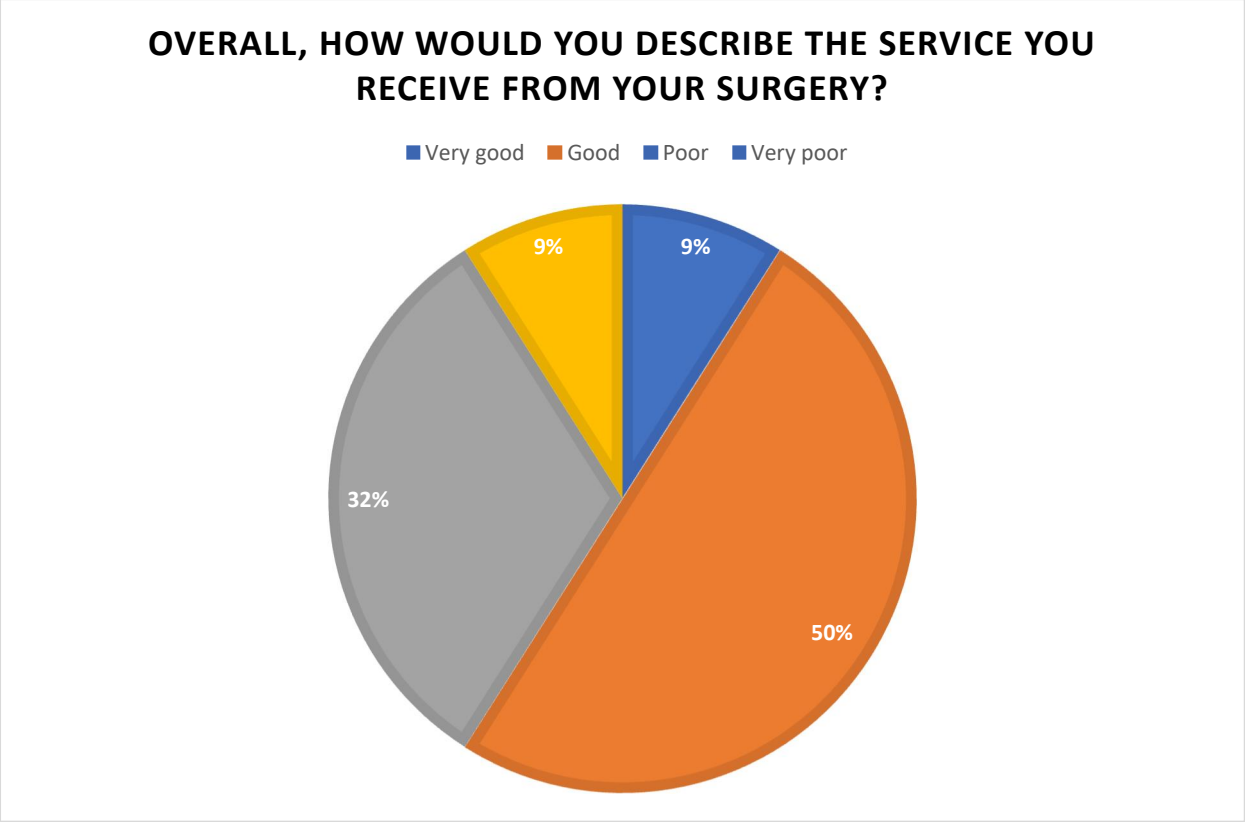
'A quiet area and longer appointment times. Also having someone with me.'

‘Not having a waiting area shared by other clinics which are not to do with my doctor. Having a quiet place.’

‘Choice of practitioner and pre-booked appts should be available.’

‘There is an online booking tool for routine as opposed to emergency appointments, but I can hardly ever find an appointment. They are usually unavailable. The online portal is not very user friendly or accessible in my mind. It should be easier to log on to and the navigation needs to be much clearer. Voice recognition to fill in forms could be useful. When being called to the GP for an appointment saying my name, putting it on a screen would be great. Another option could be a buzzer that people are given in arrival. It buzzes in their hand when it is their appointment. Like the ones at restaurants when it's time to collect your food. A quiet/sensory waiting area. A quarterly offer from my registered GP for a checkup.’

‘Appointment times should be made easier, like instead of 8am why not 1pm for people who work shifts etc. Also, some people have difficulty sleeping. So yes, different time scales.’



We then asked, 'Overall, how would you describe the service you receive from your surgery?

Responses were as follows.

'They are friendly and try to do their job but get distracted sometimes.'

'It's ok but it could be better.'

'Misdiagnosis for decades combined with their refusal to take on shared care is exhausting and hugely damaging to my mental and physical health.'

'Last year I would say that the rating would be poor, but it depends on who the staff are. Sometimes it's poor.'

'I have tried to join the patient group before and more recently online - never heard anything.'

'Really poor. I hate contacting them.'

'I think all PCNs are struggling. As a patient you are caught between the devil and the deep blue sea. It is the same everywhere.'

'They never listen properly and don't help me to keep up to date with medications or prescriptions for me or my children. I need help with organisation.'

'I made enquiries about a diagnosis over five years ago. Nothing happened about it. Now the wait for diagnosis is over two years. There are no services even if you do get a diagnosis. GPs seems to have no knowledge about autism or the implications for mental health.'

'Generally, they are very kind and helpful. My autistic nature makes me very agitated if I'm not listened to properly, but they are mostly understanding.'

'Like I said previously overall it's a good service. But there's plenty of room for improvement.'

Finally, we asked if there was anything else that respondents would like to tell us. We received the following replies.

‘I know it’s hard, but home visits should be offered to those who are carers or find the GP surgery overwhelming. Not having easy access to this option prevents people seeking medical help.’

‘I really want to see the same GP every time I go, so they understand me better.’

‘Medical professionals are dismissing ASD.’

‘More staff meetings and someone teaching them about ADHD and ASD.’

‘I was told that when speaking to a GP about my ADHD and that I was feeling overwhelmed and stressed that I should do CBT as I need to change my behaviour. I felt like this was saying that there is something wrong with me and I need to change to fit in with the rest of the world. I actually found it very offensive. I have now not been to see this particular GP since.’

‘Yes, but I’ll be here all day! The experience I’ve had with the NHS since my autism diagnosis in 2020 has been nothing like it was prior to that so I can only assume it’s because of the A word. I actually wish I’d not bothered getting a diagnosis and not fought to have the wrong diagnoses removed from my file and replaced with the correct one. It’s made nothing better! I’ve never been treated as appallingly as I have since being diagnosed. Is that universal? I’ve never asked for reasonable adjustments as I’ve not needed it before but dealing with the NHS nowadays makes me feel disabled.’

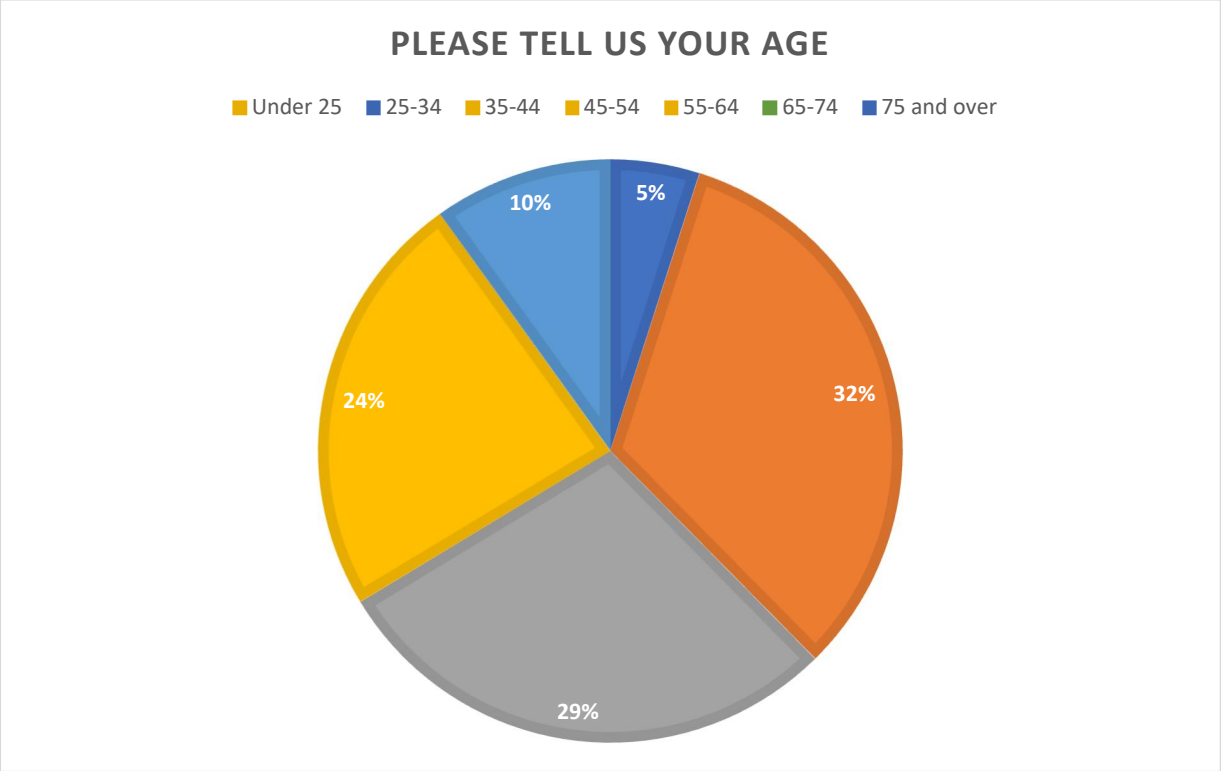
‘Yes, some people like me have difficulty speaking to others. You need the right kind of professional.’

‘I worry about my heart. Medication reviews are pretty basic. We are unlikely to disclose abnormal symptoms from our medications due to the fear that they will be taken away.’

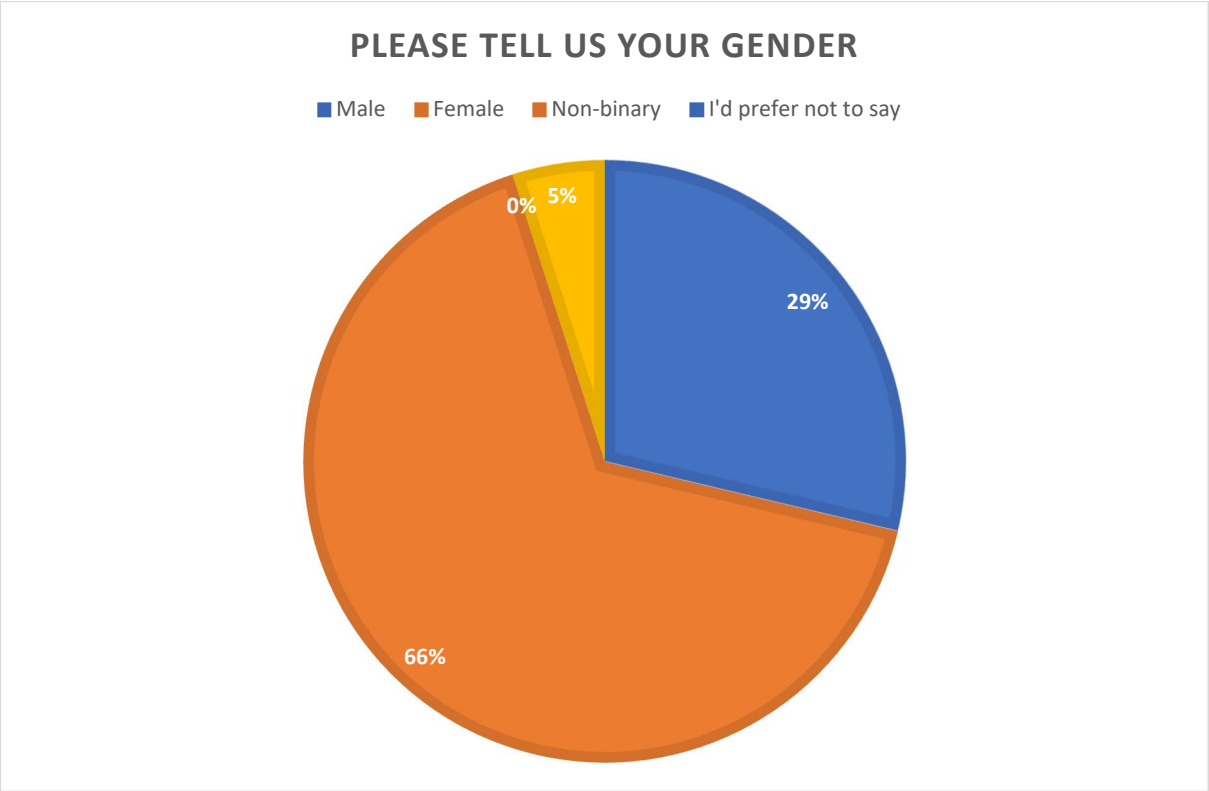
‘When I ask for specific help, I get unhelped and made to feel I am in the way.’

‘They referred me for additional diagnosis but then got the nurse to call me, but I don't like talking on phone so hung up and still don't know about my diagnosis.’

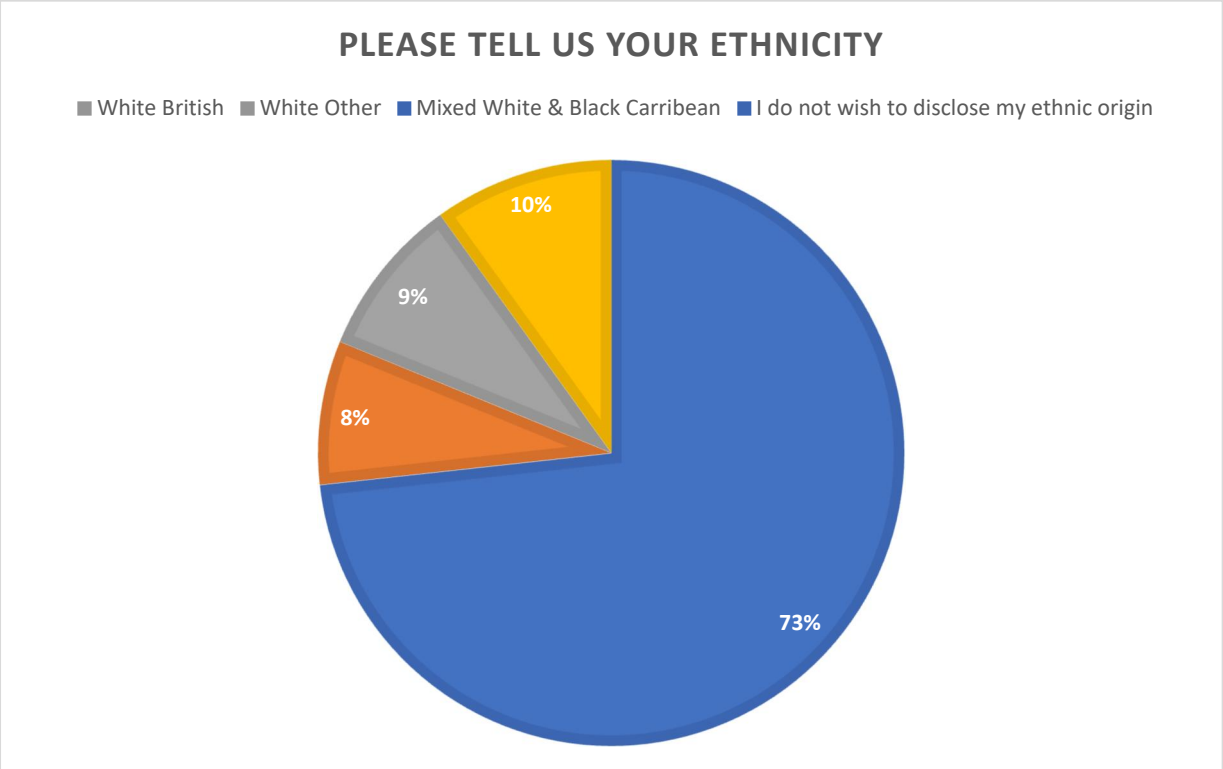
We also explored participant demographics in our engagement.



We received a good distribution of responses across the age groupings, with the majority of respondents falling within the 25-54 age bracket. This mirrors what we expected as the generational awareness of neurodiversity has risen over time.



Here two thirds of our respondents identified as female. With the remaining third identifying as male or preferring not to specify.



Almost three quarters of respondents stated that they were White British, and a significant ten per cent preferring not to say.

2.3 Interviews

Many people offered to talk to us directly and inform us about their stories in depth. We would like to thank everyone who took the time to share their experiences, helping us to produce this report. From those that we have spoken to, we would like to highlight three case studies reflecting the lived experience of people in West Essex.

Interview 1

James*

'It was only like a couple of years ago, in 2021. I did start with the NHS. So essentially, I was at home feeling very depressed and not knowing why. And I had been to the GP and stuff on a number of occasions talking about anxiety and depression. Things like that. And things just weren't getting better, and I just thought to myself, look, something's really wrong here but I can't work out what it is. It didn't make sense, so I went online and did a bunch of online tests.

I just found a website that had loads of different ones, so it had autism, ADHD, bipolar, eating disorders, all this stuff. ADHD just happened to score really highly. I phoned my mum, and she said your uncle has been diagnosed with ADHD and your cousin has been too. So it was that that kind of pieced it together. I then listened to a podcast called [something like] 'Holy ****, I have ADHD'. I listened to it and listened to the first episode, and I was in this unbelievably depressed state at home but found myself laughing. Because I was like. 'Jesus, that's it. That's it!' I have that identification, so from there I went to the doctors.'

However, instead of everything moving forward, it all started to get bogged down and go nowhere.

'They were going to refer me. I came home and about a week later I got a letter to say I had missed an ADHD appointment and I needed to get in touch with them. It didn't make any sense! I then got in touch with doctor, and he agreed.

In the end, I found out it was some kind of error, some kind of administrative error anyway. I tried to get in touch with the people who did the appointment as well, and that wasn't easy. It was online, you know, trying to get through. It was really confusing and taking so much time.

Finally, we got the letter sent to who it was supposed to go to. I then got a phone call from somebody a number of weeks later, who went through a questionnaire with me on the phone and at the end they said 'OK, brilliant, we're now going to put you forward to get you a diagnosis. We're going to refer you.' However, I was just waiting around for ages and heard nothing at all. Eventually I got an e-mail from them confirming what they'd said, but no date for an appointment.

It was at that point that I decided to have a private diagnosis. It turns out it would have been December 2022 when I would have had the ADHD assessment – more than 18 months after the referral. I needed to get the NHS to take over my medication. They wouldn't do that during my titration phase when I was being put on the medication and then being stable, but they did take it on after.'

We then talked about how James feels when going to see the GP.

'If I'm ever going to the GP, well, maybe not so much now, but certainly during all of the past, it was like I always felt like I was going to be lying to them. I was going in there, telling the truth, how I'm feeling, but I would be saying to myself 'Is it over the top? Why do I feel like this, I'm not telling the truth, I'm lying.' But I wasn't lying at all.

'That felt so weird, I would literally have to think about it again and again and again in my head to make sure I was going to say the right things and make sure that I really did stick to how I was feeling. Just because of the feeling that they won't believe or, you know, just because I think this, they'll think I'm mad. It's interesting because now the way I feel is so different, I would never think of that. I'm just going to say how I'm feeling, which would be the same outcome, but without all the worry.'

We also discussed making an appointment. James* struggles with making a call to the surgery and hates that he has to wait in a queue and then answer questions from a receptionist, so he took to a unique way of contacting them.

'It got to a place where I literally couldn't get through so often that I just stopped, and I started writing letters and putting them through their post box and then them sometimes saying I shouldn't do this – depending on who picked it up, I think! It did mean that I got a call back from the doctor sometimes so that's why it was the way I was doing it. But you know that meant I had to go all the way out to the doctor and put it in the letterbox in the hope that they would then read it and get back to me and do something.

'For people that are neurodiverse there are some particular ways that make it exceedingly difficult. If you get to the point where you're just thinking I'm just going to leave it, I'm not going to, then that's terrible because the point where you're calling a doctor is usually a point where you're feeling very unwell, or down, or low about yourself, actually and all those things make the communication more difficult. So, it's even more important to give people as many options as possible so they can feel comfortable and able to make an appointment the way that's best for them – online, e-form, phone call etc.'

The final part of our conversation was about the experience of being at the surgery.

'I suppose once you're in the GP, I'm quite lucky in that they've got a nice waiting room. It's normally pretty quiet and all that kind of stuff. Sometimes when it's busy though, it would be nice if there was a quiet zone. It's not just about neurodiversity. It's about making people feel comfortable and a relaxed environment. Some thought into that would be good.'

‘I think my GP's really good with the way it lets people know it's their turn to be seen, because it shows it on a screen, and it has a little ding as well to gain people’s attention. I think they are covering various different things for people with different disabilities. One thing I'd say is when people are in there, make sure they feel comfortable and they’re not going to miss their appointment, because that can be a real worry actually.’

Interview 2

Alex*

‘When I was younger, I went for a diagnosis through the NHS, but the school weren't quite on board with it. I must have been about 14 and I just found the assessment really hard. I didn't really feel like I was being listened to during it.

You just get more anxious sitting there. I'm sitting there with my mum and there's one doctor, but it feels quite intimidating. Even as a 14-year-old teenager who can understand this situation, it kind of feels like you're being picked apart.

‘There was forms to fill in before I went for the assessment and despite asking the school to do them, they didn’t until the last minute. My assessment was first thing Monday morning, and they didn't do it till the Friday evening; like half three, end of the day on the Friday. I felt like they just crushed it.’

After the appointment Alex* was sent a letter.

‘They said that there wasn't enough evidence to diagnose me with ADHD.’

We then discussed what it’s been like as Alex* has moved into adulthood.

‘It’s something I've been thinking about for quite a while; going and getting a diagnosis as an adult. But I think it's quite hard after that initial assessment to build up the confidence and courage to go again because I felt a bit traumatised in the first experience.

‘It's always been that I think I've got it. But, you kind of don't need a label, but you want a label, so you can understand yourself and I think after that assessment it put me off of exploring it more for a long time. I've just noticed it impacting me more and more. It was something I've wanted to do for quite a few years, but it's actually taken quite a few years to actually book. Just because, it's such a big deal. And you do feel like you are just putting yourself out there again to be knocked down.’

‘I remember having a conversation with my GP about it and she said ‘oh, why do you want to do that?’ And so again, you feel like you fill up the courage to then just be knocked down again.

So, I ended up having to go private. It was over Zoom and I felt quite at ease from the start of it and I felt listen to. I remember getting asked how it made me feel, which was quite important – it does have a big impact.

I kind of feel like when I was younger, it was trying to prove why I haven't got it. This time, it was actually 'do you know what, you might have it, just let's figure it out'. It was a lot more supportive.'

We then discussed how things might have evolved if the diagnosis at 14 had been different.

'I wanted to be a social worker then. I think if I had the right support, I could have maybe gone to university. At least got some A-levels. Whereas now I'm in a bit of a situation where no one really looks at GCSE's and I've just got eight years of work experience, which is fine and I've learned a lot from it, but I'm stuck on where to go next. But yeah, I definitely think if I got the support then I could have dealt better with my levels of anxiety.'

The final thing Alex* wanted to say was that despite the diagnosis having a positive effect, the GP's and NHS's attitude continues to make life difficult.

'I have now got my private diagnosis, but I'm struggling to get the NHS to accept it. I have to go through another NHS diagnosis. That's been quite a challenge as well – getting questioned by your GP on why you want to go through it.

I'm not really on the waiting list yet, they said about 20 months. I have enquired about doing it through the NHS 'right to choose', but the doctor was quite against it, but despite that I'm still considering it.'

Interview 3

Jack*

Jack* was diagnosed with ADHD and ASD five years ago, aged 16. I spoke to his mother, Claire*.

'As a young child he would often seem to be in his own world, sometimes he didn't seem to be bothered, didn't really want to be involved.

But I thought he was just a little boy who was a little bit different. He would be loving and gentle and I'd tell myself everything was fine.

As I look back now, I can see that as he got a bit older, he struggled to be attentive and seemed to be unable to focus on anything specific – a task at home, doing his homework and things like that. He seemed to have no attention span.'

I asked about whether anybody else such as school or their GP ever raised the matter.

'No, not until he was about 15. I mentioned something once to the GP when he was maybe about ten, and I had taken him in with a sore throat, but they didn't seem concerned about it. At the time it felt reassuring, and my worries were unfounded. Whatever it was was insignificant and was just part of his development.

‘It was eventually at a parents evening at school where I got into a discussion with his form teacher that I decided I needed to look into it for myself. My gut feeling that something wasn’t right had never gone away and I decided it was up to me to take control and work things out. The teacher had talked about a previous student that had ADHD and Autism, and so I went and looked it up.

As soon as I read about the symptoms, the behaviours, the mannerisms, all of that, it just seemed to fit. I took him to see the GP and felt a huge combination of apprehension and anxiety, but also some sort of excitement that things were going to change.

‘I was anxious that the GP would be dismissive, as they had been previously, but it was a new doctor, and they were great. I was disappointed that the referral would take three or four months but pleased to be listened to and not made to feel stupid.’

Since the diagnosis, many things now make more sense, but Claire* is still very frustrated.

‘I’m annoyed that the GP didn’t take me more seriously ten or so years ago, but they have been supportive since then. I’m not sure they understand that much about the condition though, and I still have to make his appointments for him as they make him feel anxious on the phone and don’t make it easy.

It’s the same with dentists. Although I now realise why going in the past was so difficult, they don’t seem to want to do much to accommodate him and make it easier for him. I have to continually push him to go for check-ups, and he is now going on his own, but if they just made the environment a bit better and ensured they checked and realised who it is that’s coming in, it could be so much better.’

*Names have been changed to protect participant anonymity.

3.0 Key Findings and Recommendations

Key Findings

Understanding and training

- Neurodiversity has a profound impact on people’s lives. The pathway to diagnosis has often been long and difficult and whether or not they are further impacted by learning difficulties, they all still have to constantly try and make their brain work to fit their surroundings. All interactions with healthcare providers produce specific challenges, so appreciating these, and dealing sympathetically with them through training and understanding is key.

Consistency

- To deliver excellent care, there is a crucial need to build a relationship and trust, allowing neurodivergent patients to be relaxed and open. Without conversation they will struggle to explain their concerns. Consistency of who they are seeing, the consultation room they are in, the time of their appointments, the day of the week, all means a lot.

Environment

- Neurodiversity often leads to anxiety before, during and after healthcare appointments. It can lead to appointments being missed and healthy outcomes affected. The physical and emotional environment a person finds themselves in from the moment they enter a building can make a significant difference. The receptionist, privacy, quiet space, the confidence they haven't missed their slot, etc are all factors in this.

Appointment making

- It can be difficult to remember when to call and difficult to plan ahead for those with neurodiversity. Life is very much lived in the now. Being on hold and then having to talk about why you've made the call can be overwhelming. There is increased anxiety through a sense of no priority equating to lack of caring.

Recommendations:

Staff

- Ensuring all members of staff have an understanding of neurodiversity is so important. Finding someone with neurodiversity to attend a staff training day to give them an insight into the nuances and impact on daily life that is has, would have real impact. Hearing about someone's lived experience first-hand can be profound. If this is coupled with a simple system to remind them that 'Mr. X', coming in at 11am is neurodivergent, it would be invaluable.

Approach

- Building a consistent approach can allow someone to open up and be honest about what is troubling them, mentally or physically when they're with the GP or another member of the practice. To enable this, where possible, they should be able to see the same GP on each visit, with appointments at the same time of day, on the same day of the week. Being seen in the same consultation room by the same person will reduce anxiety levels by a significant margin.

Environment

- The physical environment created by buildings - waiting rooms, open spaces, quiet spaces, private areas, notice boards and information screens all have significant impact. Most people who are neurodiverse want to slip in unnoticed, find a quiet corner, know if there are any delays, be seen by someone familiar, and quietly leave. Inevitable some buildings are better placed to be able to deliver this than others, but as and when possible, these factors should be carefully considered. Having the reception tucked to one side where visitors don't have to walk in full view right down the middle of the waiting room, and where conversations are not overheard makes a big difference from the word go. Trying to develop a system where the doctor or nurse or receptionist doesn't stand there and shout a person's name out loudly in front of everybody would also be time very well spent. There are systems that use vibrating pagers when it's your turn to be seen for example.

Appointments

- Appointment making is stressful for everybody at the moment, not just the neurodiverse. However, the impact can be very much stronger and more difficult for them to deal with. The understanding and training mentioned earlier can help with this, but it's also important to remember that the survey showed a significant demand for online bookings from this cohort. As solutions are continued to be worked on towards easing the burden on phone systems, feedback from neurodiversity patient representatives should be sought and listened to.

4.0 Conclusion

The issues highlighted in this report are not just about ongoing healthcare for people already diagnosed with a neurodiverse condition, but about ensuring more people are diagnosed at the earliest opportunity, including adults who were missed or wrongly diagnosed as children.

Understanding neurodiversity, learning to empathise with those who live with it and those who think and worry they might have it is the route to the source.

Creating an environment in and around GP surgeries and GP services where patients are sympathetically dealt with by every member of staff is the key.

There are clearly areas for improvement. In the survey, for example, 68% of respondents said reception staff are 'good' or 'very good', but 14% chose 'very poor'. These numbers can be improved with the implementation of the recommendations in this report.

Furthermore, 41% said the overall service from their GP surgery was 'poor' or 'very poor'. While we know there are more fundamental problems around GP access that are difficult to address, the percentage score here can be improved too.

While there are wider priorities around adult NHS ADHD diagnosis provision and other broad-spectrum issues beyond the scope of this report, there are straightforward provisions that can be implemented in quick time with little investment.

Online appointment making, quiet spaces, information boards and above everything else, understanding from all staff will make positive change to the West Essex Neurodiverse population.

5.0 Terminology and Acronyms

ADHD – Attention Deficit Hyperactivity Disorder.

ASD – Autism Spectrum Disorder.

CBT – Cognitive Behavioural Therapy.

DNACPR – Do not attempt cardiopulmonary resuscitation.

DNR – Do not resuscitate.

E-consult – an online medical app.

GP – General Practice or General Practitioner.

IAG Team – Healthwatch Essex's Information & Guidance Team.

ICB – Integrated Care Board.

ICS – Integrated Care System.

Locum - a person (GP) who temporarily fulfils the duties of another.

PCN – Primary Care Network.

Hertfordshire and West Essex Integrated Care System

NHS Hertfordshire and West Essex Integrated Care Board

Meeting:	*Meeting in public*	☒	*Meeting in private (confidential)*	☐			
	NHS HWE ICB Primary Care Board held in Public				**Meeting Date:**	**28/09/2023**	
Report Title:	**Minutes from Primary Care Subgroups**				**Agenda Item:**	**12**	
Report Author(s):	Multiple authors, collated by Annette Pullen						
Report Presented by:	N/A						
Report Signed off by:	Avni Shah, Director of Primary Care Transformation						
Purpose:	**Approval / Decision**	☐	**Assurance**	☐	**Discussion**	☐	**Information** ☒
Which Strategic Objectives are relevant to this report **[Please list]**	▪ Increase healthy life expectancy, and reduce inequality ▪ Give every child the best start in life ▪ Improve access to health and care services ▪ Increase the numbers of citizens taking steps to improve their wellbeing ▪ Achieve a balanced financial position annually						
Key questions for the ICB Board / Committee:	N/A						
Report History:	▪ The minutes of each sub-group are reviewed and approved at the sub-group meeting.						
Executive Summary:	Minutes from the Subgroup – attached for information only: - Primary Care Digital - Primary Care workforce						
Recommendations:	To note the minutes and notes of the sub-groups.						
Potential Conflicts of Interest:	***Indirect***	☐	***Non-Financial Professional***	☐			
	Financial	☐	***Non-Financial Personal***	☐			
	None identified			☒			
	N/A						

Implications / Impact:		
Patient Safety:	*n/a*	
Risk: *Link to Risk Register*	*n/a*	
Financial Implications:	*n/a*	
Impact Assessments: *(Completed and attached)*	***Equality Impact Assessment:***	N/A
	Quality Impact Assessment:	N/A
	Data Protection Impact Assessment:	N/A

Hertfordshire and West Essex Integrated Care System

NHS Hertfordshire and West Essex Integrated Care Board

FINAL MINUTES

Meeting:	**ICB Primary Care Digital**			
	Meeting in public	☐	*Meeting in private (confidential)*	☒
Date:	**Thursday 17th August 2023**			
Time:	**10:00am**			
Venue:	**Via MS Teams**			

Name	Title	Organisation
In attendance:		
Parul Karia	GP & Primary Care Digital Lead SW	HWE ICB
David Coupe	GP System architect	HBL ICT
Shane Scott	Associate Director of Informatics	HBL ICT
Trudi Mount	Programme Director ICB Digital Team	HWE ICB
James Gleed	Associate Director: PC Strategy & Transformation	HWE ICB
Deepa Dhawan	GP Waltham Abbey, CD Epping Forest PCN	HWE ICB
Simon James	Senior Primary Care Manager WE	HWE ICB
Ian Perry	Partner member: Digital Estates Infrastructure Lead (Chair)	HWE ICB
Louise Manders	Deputy Head of Communications & Engagement	HWE ICB
Sarah Ost	Programme Director: Digital Transformation Strategy	HWE ICB
Mefino Ogedegbe	Community Pharmacy Clinical lead	HWE ICB
Phillip O'Meara	Senior Finance Manager NAS & PC)	HWE ICB
David Ladenheim	Pharmacist PMOT	HWE ICB
Adam Lavington	Director of Digital Transformation HWE	HBLICT
Kathryn Sharpe		
Sarah Ost		
Joella Scott (Presenter)	Deputy Head of Integrated Health & Care Commissioning Team	IHCCT
Helena Russell (Presenter)	CYPMH Commissioning Team	IHCCT
Tim Anfilogoff (Presenter)	Head of Community Resilience	HWE ICB

PCD/01/23	**Welcome, apologies and housekeeping**
1.1	The Chair welcomes all to the meeting.
1.2	Apologies received from: Avni Shah, Inderjit Sunner; Stephen Muggride; Gopesh Farmah; Phil Turnock; The Chair noted that the meeting was quorate.
1.3	**Declarations of interest** The Chair invited members to declare any declarations relating to matters on the agenda: Parul Karia updated: GP in SWH and CCIO for PC HWE No new DOI to note. Chair reminded all to update DOI if appropriate/required
1.4	**Minutes from the previous meeting** The minutes of the meeting held 20/07/2023 were approved with amendment on page 3.
PCD/02/23	**Action tracker**
2.1	The action tracker was reviewed, updates discussed and noted: **See action tracker document for full details.**
2.2	**PCD/05/23 – Operational Update** – The questionnaire has been sent out, deadline for returns is 18/08/2023, to update at September meeting. **PCD/04/23- Risk Register for PC Digital – ongoing**. **PCD/04/23 – Clinical Reference Group Meeting - Accessible Technology** – PK updated under agenda. Closed. **PCD/04/23 – Com Pharmacy and ICS Interfaces Meeting –** *re interoperability and SystmOne* – Ongoing **PCD/04/23 – NHSE GPIT Review** - not yet received final version and will bring to group once received. **PCD/04/23** – **Assistive Technology Meetinhg – High level overview of asistive technology**. – *Set up meeting/working group* with organisation involved to discuss next steps - PK updated as agenda. Closed. **PCD/04/23** – **Assistive Technology – High level overview of the AT** – *IP to meet with LS to explore integration of practices NHS mailbox with their clinical systems* - IP to update Sept. **PCD/04/23** – **Assistive Technology Meeting** – *PK/GP explore automation options for tasks currently performed on documents.* – PK/GF to update Sept.
PCD/03/23	**New Digital Gateway Provider – Herts CYPMHS (Joella Scott)**
	Joella presented to the group the Children, People's Mental health Services Redesign and Digital Gateway. Highlighting the need to improve the customer journey, increase the access and the way we enable people to get into the system, have better advice, guidance, and information, improve digitalisation by working with stakeholders from across the system. They have procured an organisation called Mindwave Ventures, a web-based system, with a website landing page/gateway, Digital Access Gateway, and a Professional portal. JS to update progress in 2-3 months. JS happy to have further conversations, email: joella.scott@hertfordshire.gov.uk CYPMHS digtial gateway and front do
PCD/05/23	**Social Prescribing & Access – Tim Anfilogoff**
	TA presented firstly on Digital inclusion via the voluntary sector. *Staying Connected (Herts)* and *Digital Share (WE)* was funded by the captain Tom money that should have ended in February but was extended through the ICB until March 24, therefore giving an opportunity to think about what we want following on from that, both have focus on recycling kit, on training, on technical advice and free data and including social prescribing through Link workers. Charities get donations of laptops and other kit, but this is not coordinated at the moment and would be useful to join that up. Therefore, what and how to fund past March 2024.

	Secondly, what systems do we need to demonstrate the population health outcomes from social prescribing. The group are having strategic discussions around digital priorities and digital inclusion and have commissioned some work around it, however, feel that we do not really know how big the problem is. TM commented, the need to link in TA and making sure that PC links to all those resources. TA added that as part of the Health Creation Strategy, that is being negotiated between the ICS and the voluntary community, faith, social enterprise sector, there is a strand called 'no wrong door' and that is about making sure it shouldn't matter if you go to a library, GP Surgery, Benefits Office, CAB. TA advised they are starting to use the Digital Exclusion Risk Tool, to see those that are digitally excluded, data so far reflects the rural areas being most excluded and working with the integrated neighbourhood teams and link workers being important. TA presented the slides to reflect the PHM Data from Social Prescribing/VCFSE - Evidence currently 25% reduction in GP appointments where Social Prescribing is happening.  digital share and staying connected.ppt  sp take up and data.pptx
PCD/06/23	**Feedback from Clinical leads and others key meetings**
4.1	**National/Regional - GP IT review**: PK updated: • GF been involved in discussions around virtual wards and will be attending the Virtual Wards Steering Group to ensure a primary care voice in the room. • GF has proposed his practice to take part in a Pilot with the Assistive Technology team. • Digital Literacey and Digital Skills in workforce, PK has met with Paul Bradley, Consultant Psychiatrist who works with HPFT, and they have developed a Digital Skills Wheel to assess the digital literacy within their workforce. PK to work on a delivery plan to assess digital literacy within the Primary Care Workforce. PK to meet with TM & GF to discuss further. • Attended a meeting and discussed the will across the ICB to be leaders and innovators as far as AI and Automation are concerned. In SWH the Digital team, along with HBLICT has supported a couple of pracatices to try out a product called GP Automate, DC & PK are visiting a practice that is trialling it to see what happens on the ground. • Electronic Prescribing in secondary care – seen slides that have been published and this still feels long way off. • PK and TM have started conversations with regard to the commissioning of POD, to see how the digital elements and interfaces with other aspects of primary care. There is a large gap in understanding of what is actually being used by those systems, and as an ICB what is needed to interface • Health Inequalities, PK visited The Watford Workshop, funded by ASC, HCC. Feels there is a hugh unmet need from a Digital Perspective, would be good to get mapping, to help with Digital Literacy and promotion of NHS App. • Communicatins – how do we tell GPs, Clinicians about what is being talked about as well as patients. • EMIS – A SWH issue,(and National problem), increasing unrest with EMIS as a clinical system. TM Updated: • **National Report on GPIT** – not received final version and will bring to group once received.

	• **Next Steps for Digital Roadmap** – Looking to bring in resource, PK & TM started to look at NHS App, inclusion etc. meeting with West Herts to start conversations around secondary and primary care.
PCD/07/23	**Operational Updated:**
7.1	**HBLICT Updates from Key Programmes** (SS/DC) • EMIS System crashes should be solved with 64bit upgrade and should be solved by early Sept. • Laptop Allocation – questionnaire went out last week and deadline 18 August. • EMIS-X test sights, has been put back to mid Sept. • AccuRx Booking Module – DC & TM meeting with AccuRx on 23 August to look at options. • SMS Latest Data – HWE looking to go live on 4th September. TM/GM & DC have met to look at getting the Comms out asap to include PPG groups etc. • Two test sites have been identified and a plan of action for getting their patients to use the NHS App more, and also use social media, website changes, Facebook, X, patient posters etc. This will be monitored to see if this makes a difference to numbers using the NHS App. • **The panic button (SS)** - there has been a rollout for the panic button replacement for the EMIS funtionality, this has now been completed in SW & ENH. Agen has been paid to roll out in WE. • **Wi-Fi in WE –** SS advised that they have started engaging with sites that do not have wi-fi and these should be up and running shortly, the team will move onto all those experiencing problems in WE. • **M365** – Microsoft Licence expires end September**.** Taken part in national procurement and this has been awarded to Insight. Team will be meeting with Insight, expected to be a three-year contract that will be called off annually. **Cloud Based Telephony** (TM)/SS • awaiting next steps for engagement with procurement hub. **Patient Records Access** (TM) • reminded the group, if a practice is an EMIS practice, and have not yet booked in their 'enablement slot' for Patient Record Access the practices will have to manually book on EVERY individual patient. Comms have gone out and reminders given at several meetings. TM will send a reminder to practices that have not yet booked. **HWE Back-up solution** (SS) • SS asked group to look at the Back up Solution paper in order to move forward. HWE Backup Solution.pdf •
PCD/07/23	**Finance Report update**
7.1	PO Provided report below: HWE ICB PC Digital Finance Report Augus
PCD/08/23	**Any other business**
8.1	None
PCD/09/23	**Date and Time of next meeting**
9.1	**Thursday 21st September 2023 – 10.00 am**

Hertfordshire and West Essex Integrated Care System

NHS Hertfordshire and West Essex Integrated Care Board

DRAFT MINUTES

Meeting:	**ICB Primary Care Digital**			
	Meeting in public	☐	*Meeting in private (confidential)*	☒
Date:	**Thursday 20th July 2023**			
Time:	**10:00am**			
Venue:	**Via MS Teams**			

MINUTES

Name	Title	Organisation
In attendance:		
Inderjit Sunner	GP / PCN Rep for ENH	HWE ICB
Parul Karia	GP & Primary Care Digital Lead SW	HWE ICB
David Coupe	GP System architect	HBL ICT
Shane Scott	Associate Director of Informatics	HBL ICT
Trudi Mount	Programme Director ICB Digital Team	HWE ICB
James Gleed	Associate Director: PC Strategy & Transformation	HWE ICB
Deepa Dhawan	GP Waltham Abbey, CD Epping Forest PCN	HWE ICB
Kolade Daodu	Clinical Director, Stevenage South PCN	HWE ICB
Ian Perry	Partner member: Digital Estates Infrastructure Lead (Chair)	HWE ICB
Phil Turnock	Managing Director	HBL ICT
Sarah Ost	Programme Director: Digital Transformation Strategy	HWE ICB
Mefino Ogedegbe	Community Pharmacy Clinical lead	HWE ICB
Phillip O'Meara	Senior Finance Manager NAS & PC)	HWE ICB
Stephen Muggride	Contracting Manager	HWE ICB
Abbeygale Langham	Admin Support WE	HWE ICB
Gopesh Farmah	Digital Clinical Leads	HWE ICB
David Coupe	GP IT Solutions Architect	HBLICT
Cathy Galione	Head of Primary Care Transformation, Integration, Development and Delivery ENH	HWE ICT
Jaime Cranny	Primary Care Co-ordinator	HWE ICB

PCD/01/23	**Welcome, apologies and housekeeping**
1.1	The Chair welcomes all to the meeting.
1.2	Apologies received from: David Ladenheim, Sara Lingard, Avni Shah, Anup Shah The Chair noted that the meeting was quorate.
1.3	**Declarations of interest** The Chair invited members to declare any declarations relating to matters on the agenda: None declared. No new DOI to note. Chair reminded all to update DOI if appropriate/required
1.4	**Minutes from the previous meeting** The minutes of the meeting held 15/06/2023 were approved as an accurate record.
PCD/02/23	**Action tracker**
2.1	The action tracker was reviewed, updates discussed and noted: **See action tracker document for full details.**
2.2	**PCD/05/23 – Operational Update** – The surveys have now been completed and a meeting is taking place on 21/07/2023 to discuss the comms to go out to practices. **PCD/04/23- NHSE GP IT Review –** The report is due out on 28th July and output is still outstanding. **PCD/04/23 – Accessible Technology** – Update given under agenda item **PCD/04/23 – PC Digital Roadmap** – Update given under agenda item **PCD/05/23 – Risk Register –** Ongoing **PCD/07/23 – EMIS Update** – Shane Scott noticed this was a duplicate action and group agreed for it to be closed
PCD/04/23	**Feedback from Clinical leads and others key meetings**
4.1	<u>National/Regional - GP IT review</u> The report is due out on 28th July and output is still outstanding.
4.2	<u>Assistive Technology meeting</u> On 13th July a meeting took place with strategic leads. Technology to help monitor people at home, to anaylyse movements and therefore see if they are not functiontioning as they would normally and therefore put in an intervention to stop it from escalating. The pilot ended in March and has been approved to roll out across Hertfordshire. There will be four practioners to view data and offer support. The social care ask will be rolled out by November. The health practitioners also want to be part of the team, but they need cohorts with both a healthcare and social care needs. Their aim is to focus on specific groups of patients. There are discssions taking place to see if this technology can be linked with other areas of primary and secondary care. The projected number of patients they want to support is 6000 across the region. PCNs are being asked to put forward patients they think will benefit from this. This is seen as a vey promising workstream, and discussions on what clinical lead can help take this forward needs to take place. Gopesh and Parul will attend monthly meetings and then feedback to this group.
4.3	<u>Update on Digital Roadmap</u> The paper was sent out this week with the next steps on it. The purpose of the document is to show the prirorities for the transformation, the system development fund areas of work and there are seven priorities.

	HWE PC Digital Priorities 2023 v0.6.pp **Action: Parul proposed that Digital Inclusion be moved to priority one, and group agreed.** **Action: Trudi Mount add to document that these priorities support both the primary care dleivery plans and access recovery plan**
PCD/05/23	**Primary Care Access**
5.1	Patient Access Patients to be able to see their recoird via the NHS app, systemOne or Emis. 19 practices are live, and other practices now need to opt in. SystemOne can automoatically do this but Emis practices needs to fill out a form. A message went out in the GP bulletin last week and a communication from the ICB will follow next week.
5.2	Patient Electronic Registration This is about enabling patients to register electronically via a link on the practice website. Once the form has been filled out, an email will be sent to the practice. If the patients already have the NHS app, they won't need to show any form of ID as this would have had to be done once registering on the app. NHSE are very keen for practices to sign up for this, so far 15/16 have done so.
5.3	Cloud Based Telephony Currently working HBLICT and the next practices who are being prioritised for this. There is approximately £1 million for this, however this will not cover all practices. Therefore a criteria of how the funds will be spent needs to be decided. There is a concern that when patients have access to their records that this is going to cause a lot more work for practices in terms of the amount of questions it will generate from patients, as well as patients being able to see blood results when practices are closed and have to worry about them until they are able to speak to someone.
PCD/06/23	**Operational Update**
6.1	HBL ICT updates from key programmes **Staff and Patient WIFI** - Shane will be bringing a paper to this group regarding a propoposal for patient wi-fi. There are some areas (Walthan Abbey Health Centre) where staff cannot get any access to wi-fi either. Plabototomists at Waltham Abbey Health Centre cannot access blood forms and patients cannot use online check in. Patients are being turned away for not having their forms but are unable to download them due to wifi issues. Laptops cannot be plugged in anywhere in a practice as this creates cyber issues. **HSCN Connections** – the contract expires in January 2024. A different way of providing this is being looked into. A Defined Wide Area Network was disccused where by instead of every site having a HSCN connection, only one in ten will and all other sites will have internet connections. This will mean more flexibility around the network and reduce costs. **EMIS Web** – EMIS is continuing to cause problems. They are releasing a PC Health Check tool to diagnose issues and this is being rolled out soon. The EMIS panic button is going to be removed soon and the replacement is called SAFE, which is produced by a company called Code Gate.

	EMIS X – The roll out for this on test sites will be in August **AccuRx** – The booking module contract is ending in December 2023. Discussions to take place on how this is used and whether the contract will continue. **NHS App Push Notifications** – This would mean that any notifications would come through the NHS App rather than a SMS message. In May, HWE spent £73,900 on SMS costs. This is considered a quiet month and gets much higher in the winter months. After a pilot ran to see the difference between the way messages are sent, it showed 6.9% of costs could be saved if sent via the NHS App. This is now going to be a national roll out. From September all these messages will be sent out via the app, and if not receievd within 3 hours it will fall back and send out a SMS message.
6.2	Arden and Gem update on contract This has been escalated to the finance national executive with NHS England. They have acknowledged the case as it is unusual circumstances due to the boundaries around Hertfordshire and West Essex. They have agreed in principle to move away from Arden and Gem and move to HBLICT, however this has not been guaranteed. They are going to set up an exceptions process which will involve a panel. In the interim the current contract with Arden and Gem will be extended. Once approval for migration has been given, it will be a 6-month migration period to enable to transition of the 30 practices.
PCD/07/23	**Finance Report update**
7.1	The budget for 23/24 is £7.5 million. Year to date there is a £22,000 overspend but this could change. **Action: PO to send a breakdown of spending to the group. This should be a standing item on the agenda**
PCD/08/23	**Any other business**
8.1	None
PCD/09/23	**Date and Time of next meeting**
9.1	Thursday 17th August 2023 – 10.00 am
PCD/10/23	**The meeting closed at 12.07**

HWE ICB PRIMARY CARE WORKFORCE IMPLEMENTATION GROUP

27th July 2023

1:00pm – 2:30pm

Microsoft Teams Meeting

Attendees		
Dr Nicolas Small (NS)	Training Hub Clinical Lead **(Chair)**	Hertfordshire & West Essex ICB
Joyce Sweeney (JS)	Head of Primary Care Workforce	Hertfordshire & West Essex ICB
Jane Scotter (JnSc)	Training Hub Operations Manager	Hertfordshire & West Essex ICB
Dr Sarah Dixon (SD)	Primary Care Workforce GP Clinical Lead	Hertfordshire & West Essex ICB
Cathy Gleeson (CG)	Lead Pharmacist – Strategy and Pharmacy and Allied Health Professions Workforce Development Pharmacy & Medicines Optimisation Team (PMOT)	Hertfordshire & West Essex ICB
James Gleed (JaGl)	AD Primary Care Strategy and Transformation	Hertfordshire & West Essex ICB
Helen Bean (HB)	Education & Workforce Manager	Beds and Herts LMC
Hannah Cowling (HC)	Associate GP Dean for HWE, HEE	Hertfordshire & West Essex ICB & Health Education England
Apologises		
Avni Shah (AS)	Director of Primary Care Transformation	Hertfordshire & West Essex ICB
Lucy Eldon (LE)	ICS Primary Care Clinical Nurse Lead	Hertfordshire & West Essex ICB
Mark Edwards (ME)	Associate Director for Workforce Transformation	Hertfordshire & West Essex ICB
Louise Casey (LC)	Training Hub Operations Manager	Hertfordshire & West Essex ICB
Dr Jayna Gadawala (JG)	Primary Care Workforce GP Clinical Lead	Hertfordshire & West Essex ICB

1.	**Welcome & Introductions** Confirmation that meeting is quorate. Apologises and welcome.
2.	**Declaration of Interests** There were no declarations of interest.
3.	**Meeting Notes from the last meeting on 22nd June 2023** The minutes of the meeting confirmed as accurate. No amendments requested. **Action Log Review:** **Action 129: Tier 2 Visa Support –** NS informed that Hannah Baker Hannah.baker11@nhs.net is the dedicated person from BLMK working on Tier 2 visas. Suggested making contact with Hannah. JS –

	advised that a how to guide was shared in the recent regional training hub meeting. The guide has been added to Training hub website and circulated to Primary Care for information. **Action 135: Mapping Data Collection –** JS to have a demonstration of QLIK SENSE, new workforce planning platform to be implemented by workforce transformation team. Close. **Action 136 & 137: Nurse Compassionate Appraisals –** Paper to be completed and returned to the WIG. Close. **Action 138: Quality of Placements –** to return to WIG with update / paper. Close.
4.	**Workforce Training Data** Deferred to WIG meeting on 07/09/2023.
5.	**Primary Care Awards – HWE Celebrating Primary Care Achievements 2023** Closing date for applications 4th August 2023, working to a tight deadline and could extend closing date depending on the number of nominations. Further communications via the Training hub website and the bulletins to be used to circulate the information. Contact to be made with Helen Musson, Primary Care Workforce Project Manager, and Scott Downham, Primary Care Workforce Clinical Pharmacist Ambassador to ensure that Pharmacy is included, as well as Dental and Optometry and the other primary care teams. The awards ceremony will take place virtually on Wednesday 11 October 2023, 7:00 pm – 8:30 pm. Jane Halpin and Paul Burstow have confirmed their attendance and will be doing the welcome and closing of the event. NS would like to have a short vignette for all those who have been shortlisted. JS confirmed that this work will be incorporated in the production plan for the evening.
6.	**Primary Care Careers Fair** The HWE primary care careers fair will take place on 21 September 2023, 10:00 – 14:00 pm at the Fielder Centre, Hatfield, Hertfordshire. The plan is to have a market stall area, these will include Apprenticeships in primary care, Nursing careers in GP Practices, Community Pharmacy, Optometrist and Dental, with many more to follow. University of Hertfordshire, and Anglia Ruskin and HCT. LMC have been invited, along with PCNs and Practices. Practices / PCNs will have the opportunity to recruit for any vacancies that they may have. NS asked for social media, radio such as 3 counties any local newspapers to be explored as a way forward with promotion of the event. The main area will have refreshments throughout the day, the drop-in area will run sessions which will include 1:1 support around CVs and interview skills. There will be two rooms that will be used as interview areas, for Practices / PCNs who would like to discuss current vacancies with potential candidates. There will be specialist talks, with a Clinical Director introducing Primary Care, and an introduction to apprenticeships, non-clinical careers in primary care and information about Hertfordshire as a place to live and work.
7.	**Enhanced GP Fellowship Programme 2023**

	Applications are now open for the next round of the enhanced fellowship and the updated information is now on the HWE Training Hub website (click here). Team are keeping a list of expressions of interest and any questions that arise, so as to be able to keep abreast of all interest. First 5 Leads (Dr Ankush Sachdev & Dr Jessica Hansell) have been attending VTS meetings and generating interest with this including the New to Practice programme. Interviews are planned for the autumn, with eight spaces to fill on the programme. The provider list is a work in progress at the moment – having different providers opens the options on the placement offer, such as Herts Community Trust offer Hospital at home, and frailty. Currently contacting GP Fellows who have completed placements previously to try and obtain testimonials. NS highlighted that we need to think about the specialities that are the priorities of the ICB, so we cannot accommodate 20 people wanting to do dermatology. However, we do need to accommodate opportunities that are most likely to retain GPs in Primary Care – in particular those at Mid-Career who are potentially facing burn-out, working 8 sessions for years and want to try something different. They could transition to 4 – 6 sessions, enabling staff retention and engagement. Team liaising with Finance to ensure correct processes are in place for programme payments.
8.	**GPN Update** Deferred update
9.	**Pharmacy Development Update** NHS England Community Pharmacy independent prescribing pathfinder bids still waiting to hear if we have been successful. Working with Scott Downham and Leen Kubba to increase the quantity of clinical placements, sending out expressions of interests with a view to engage with champions. Hoping to engage three pharmacists who have a GP background and three with a community pharmacy background; they will be helping to support the development of placement provision across the patch. Working with Helen Musson on ways that the Local Pharmaceutical Committee can support.
	Any Other Business JS updated on a recent meeting with Mark Edwards and Sharon Bromley to ensure that the Training Hub and Workforce Transformation team are working together on projects such as apprenticeships and student placements and not duplicating work. Looking to map across both teams, looking at roles and responsibilities and how to get everyone together for a half-day away day to focus on improving communication and workflow, we need to be cohesive to avoid confusion. SD suggested that as some of the larger scale meetings, if it would be possible to have a primary care item on the agenda, as we are a huge proportion of healthcare, but usually do not have a voice amongst the larger providers in the room. JaGl agreed with SD's point, primary care as it looks like we are not engaging, so we need to have a more balanced agenda so there will be a return on the time invested.

	Discussion covered the issues of the payments to GP who undertake the ARCP Panels and IR35. This is still a problem as the panels are not considered consistent employment. Meetings continue with finance and HR. NS not wanting to change the membership of the WIG but wants it to be as strategic as possible when we return in September, agenda to be reviewed to reflect this.
	Date of next meeting: 7th September 2023 13:00 – 14:30

Future Meeting Dates

7th September 2023	13:00 – 14:30
26th October 2023	13:00 – 14:30
27th July 2023	13:00 – 14:30