Unity Insights

Child-Parent Screening Service

Evaluation report

April 2025

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Executive summary

Context

Familial hypercholesterolemia (FH) is a genetic condition resulting in high atherogenic low-density lipoprotein (LDL) cholesterol levels in the blood, increasing the risk of myocardial infarction and stroke (British Heart Foundation, n.d.; NHS England, n.d.-a). The NHS *Long Term Plan* (n.d.) aimed for 25% of FH patients to be identified in the next five years (2019 to 2024) through the NHS genomics programme. Testing children for FH allows both parent and child to be identified and treated together. This is commonly known as the child-parent screening service (CPSS), which was implemented between October 2021 to October 2024.

Unity Insights were commissioned by Health Innovation North East and North Cumbria to understand the impact of the CPSS within 67 GP practice pilot sites across NHS England. Survey data was collected from key stakeholders and semi-structured staff interviews were held. Data was analysed through frequency distributions and thematic analysis where appropriate. Quantitative and statistical analysis of screening data was also completed.

Key results

There were two diagnoses of FH out of all 1,820 child screenings completed (0.11%), yielding similar results to Wald et al. (2016), which utilised a similar methodology (0.20%) and screened 10,095 children in the UK. Statistical testing was insufficiently powered to detect a significant difference based on sample size.

Levers for success

- Staff and parents must understand the need for the CPSS to '*buy-in*' and complete the screenings
- Implementation is more feasible at larger sites with greater resources
- All staff involved in the CPSS must receive comprehensive training on their role in the service to aid understanding

Barriers to success

- Staff did not always know who to contact when issues arose
- GP practices were provided with £10 for every screening completed and were given a point of care (POC) device free of charge as an incentive, but not all saw these as valuable
- Errors in the POC device necessitated retesting, reducing uptake due to the test's invasiveness

Recommendations

Based on the lessons learned, the optimal strategy involves the following adaptations:

- Create a campaign to raise awareness of FH
- Review the incentives provided
- Expand the CPSS gradually based on GP practices with existing cardiovascular disease (CVD) interventions or a high number of one-year-old patients
- Tailor training to each staff role
- Ensure accurate data collection
- Signpost all contacts and improve the level of support for GP practices
- Regularly measure patient and staff satisfaction levels

Conclusion

The CPSS yielded similar findings to Wald et al. (2016). Variations in uptake indicate that some GP practices could enhance their performance further. Improving communication and buy-in could boost screening rates in the CPSS, advancing the NHS *Long Term Plan* (n.d.) and enabling earlier FH diagnoses, allowing individuals to make vital lifestyle changes before it is too late.

1. Introduction

1.1. Context

Familial hypercholesterolemia (FH) is a genetic condition resulting in the liver being less able to process cholesterol properly. This leads to high atherogenic low-density lipoprotein (LDL) cholesterol ('*bad*' cholesterol) levels in the blood (British Heart Foundation, n.d.). Thie build-up of plaque in the arteries increases the risk of myocardial infarction and stroke as blood cannot move around the body easily (NHS England, n.d.-a).

Approximately 220,000 people in the UK have FH, but less than 8% are currently diagnosed (NHS England, n.d.-b). Without treatment, the incidence of myocardial infarction is approximately 50% by the age of 50 in men and approximately 30% by the age of 60 in women (Marks et al., 2003). Identifying individuals with FH before the disease develops is crucial to enable interventions such as lifestyle modifications and pharmacological provision (for example, statins) to be introduced before symptoms worsen. The NHS *Long Term Plan* (n.d.) set a target for 25% of FH patients to be identified through the NHS genomics programme (2019 to 2024); currently less than 8% of FH cases are currently diagnosed.

1.2. The Child-Parent Screening Service

FH is a genetically inherited condition, meaning that each affected person will have at least one affected parent. Testing children for FH allows both parent and child to be identified and treated together. This is commonly known as a child-parent screening service, or CPSS.

Child-parent cascade testing has previously been completed in Australia, where three children out of 448 screened (0.67%) were diagnosed with FH through measuring cholesterol levels and genetic testing (Martin et al., 2022). Upon screening their family members, a further five individuals were diagnosed with FH. Within this study, 96% of parents would screen their future children for FH.

In the UK, a previous pilot implemented the CPSS to screen 10,095 children across 92 GP practices in the UK between March 2012 and March 2015 (Wald et al., 2016). Overall, 80 patients (40 children and 40 adults) were diagnosed with FH. In this pilot, in addition to an FH diagnosis being made due to high cholesterol and genetic confirmation, a diagnosis was also made if two cholesterol tests yielded high cholesterol levels, or if genetic FH was identified, but the patient did not have high cholesterol. There were 20 children with genetically identified FH who also had high cholesterol (greater than or equal to 1.53 multiples of the median [MoM]) out of all 10,095 screenings completed (0.20%; Figure 1).

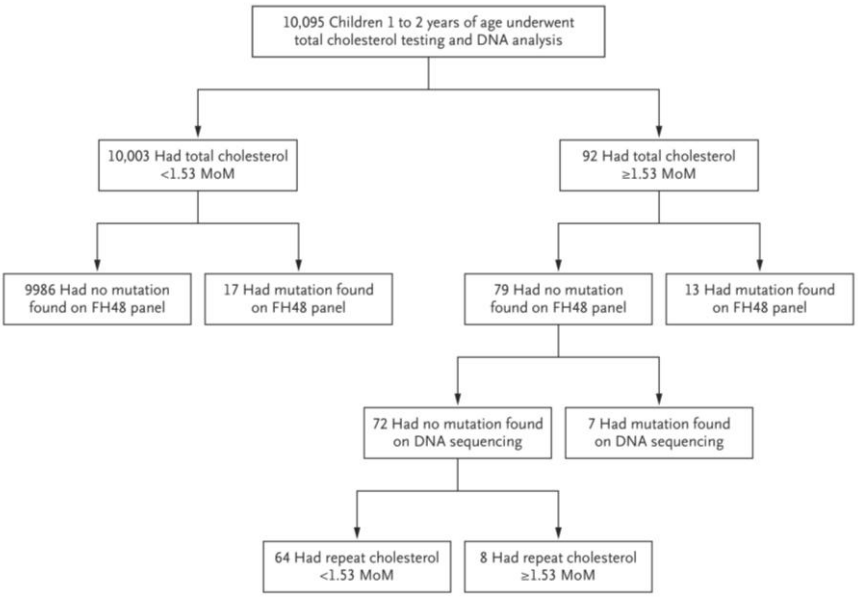


Figure 1: The breakdown of diagnoses from Wald et al. (2016).

Following an FH diagnosis, parents are offered statins immediately, whereas children are offered statins from the age of 10 onwards (National Institute for Health and Care Excellence, 2008). Both parent and child are recommended to adopt healthy lifestyle adjustments such as a diet low in saturated fats and smoking cessation.

Parents were asked about their experience of the pathway in Wald et al. (2016). Here, 84% agreed to have their child tested during their first routine vaccination appointment and 94% would have a second child screened if screening were routinely offered.

The success of the previous CPSS programme resulted in the Health Innovation Network (HIN), led by Health Innovation Norh East and North Cumbria (Health Innovation NENC), developing a real-world pilot across a number of participating sites in England, beginning on 20th October 2021 and ending 31st October 2024. An implementation manual was provided to GP practices, HINs, and genomic laboratory hubs (GLHs) to provide guidance on how to implement the CPSS.

HINs invited GP practices to participate in screening for FH. If they did not already have a device, GP practices were provided with an Afinion point of care (POC) device to measure cholesterol levels from a heel prick sample. Samples with cholesterol levels equal to or greater than 5.3 mmol/L — corresponding to the 95th percentile, or approximately 5 out of every 100 children, as defined in the implementation manual — were referred to GLHs for FH testing. GP practices were initially given £3 for every child screened, or £5.50 for every child screened if the GP practice already had their own Afinion POC device. From December 2022, this increased to £10 per screening in an effort to increase the number of GP practices engaged with the CPSS. Overall, 67 GP practices across 7 HINs agreed to participate in the CPSS across the three years. Within this, GP practices started implementation at different times, and some withdrew from the CPSS prior to the programme ending.

1.3. Purpose of the report

The current report provides the findings and key recommendations from the evaluation conducted by Unity Insights into the impact of the CPSS within GP practice pilot sites across England. The evaluation assessed the effectiveness of the delivery and impact of the Child-Parent Screening Service against the objectives, which were defined for the programme. These were:

- Implementation of a clinical pathway for child parent screening to test 5,000 children by October 2024
- Numbers of children identified as positive for genetic FH and family members through cascade testing[1]
- Acceptability of the service to healthcare professionals (HCPs) running the CPSS in primary care
- Acceptability of the service to parents/guardians
- Most efficient delivery model/pathway
- Uptake of service across different postcodes

2. Methodology

2.1. Analysis and evaluation approach

The purpose of this evaluation was to assess the implementation, delivery, and impact of the CPSS, including its contribution to the NHS *Long Term Plan*'s cardiovascular disease (CVD) 10-year ambition (n.d.), the development of an effective clinical care pathway, healthcare professionals' capacity and competency, and key programme metrics to inform future improvements. Through a mixed-methods design using quantitative and qualitative analytical methods, the evaluation aimed to understand:

- The most successful clinical care pathways and why they were successful
    - Whether the service was able to achieve its initial aim of testing 5,000 children by October 2024
    - The number of children identified as positive for FH, and subsequently, the number of family members identified through cascade testing

[1] Please note that only index testing was examined in the current evaluation; cascade testing figures were not provided.

- The most optimal implementation strategy for GPs, GLHs, HINs, children, and parents and guardians
    - Acceptability of the CPSS service
    - Uptake of the service, including across different geographic areas
- The lessons learned from the implementation of the CPSS
    - The levers for and barriers to successful implementation of the CPSS
    - How the lessons learned can inform future service development and delivery

Evaluation questions

The evaluation questions were as follows:

1. Which clinical care pathways were the most successful and why?
    a) Have the identified metrics and targets been achieved? What metrics would define future success?
    b) What was the optimal strategy for implementation for specific groups?
        i. GPs
        ii. GLHs
        iii. HINs
        iv. Children and parents/guardians
2. What lessons have been learned from the implementation of the CPSS?
    a) What were the levers for and barriers to successful implementation of the CPSS?
        i. Was the POC analyser easy to use and well received?
    b) How can these lessons inform future service development and delivery?
3. To what extent has the CPSS contributed to the NHS *Long Term Plan*'s (n.d.) ambition for 25% of predicted FH patients to be identified by 2024?

2.2. Quantitative analysis

Screening data

Health Innovation NENC provided data surrounding the number of screenings GP practices completed each month from November 2021 to October 2024. Three GP practices were removed from the analysis as these GP practices completed no screenings and returned the Afinion POC device. Data was analysed through frequency distributions, where the number of screenings was summed for each GP practice and each HIN. Uptake rate was also calculated by dividing the number of screenings completed in each GP practice by the number of one-year-olds registered in

each GP practice in the same time period using *patients registered at a GP practice* (NHS Digital, 2024b) and aggregated to each HIN.

Statistical testing

Fisher's exact test was conducted to determine if the observed difference in the number of FH diagnoses among completed screenings, compared to the expected number, was statistically significant ($p < 0.05$). To assess robustness, Chi-squared test findings were completed and compared to fisher's exact test, where a similar finding indicated robustness. Statistical power was also calculated to determine the minimum number of screenings required to achieve results comparable to that of Wald et al. (2016).

Health inequalities

Ethnicity

Eligible pilot population for participating GP practices

The ethnic breakdown of patients at each GP practice engaging in the CPSS pilot (completing one or more screenings) was identified through *National General Practice Profiles* (Department of Health and Social Care, 2024). This was compared to the number of registered one-year-olds in each GP practice from November 2021 to October 2024 using *patients registered at a GP practice* (NHS Digital, 2024b) to identify a proxy for the total number of children that could be screened within each ethnic group and GP practice. This was summed for each participating HIN.

Eligible population across all participating HINs

The percentage breakdown of one year olds in each ethnic group by HIN was identified within *Ethnic group by age and sex in England and Wales* (Office for National Statistics, 2021), where local authority codes were mapped to HINs to identify a proxy for the total number of children eligible to be screened within each HIN. This was compared to the proxy ethnic breakdown of registered one-year-olds in the participating HINs for the pilot.

Statistical testing

P-values assess statistical significance, with a threshold of $p < 0.05$ set for the current evaluation. A *p*-value represents the probability of obtaining observed results due to chance rather than due to the intervention in question.

A binomial statistical test was conducted to determine whether the assumed proportion of one-year-olds in each ethnic group within GP practices participating in the CPSS in each HIN differed from the corresponding proportion of one-year-olds in each ethnic group in that HIN overall. In interpreting the *z*-statistic, a value greater than 1.95 or less than -1.95 suggests a substantial departure from expected outcomes, supporting the presence of a meaningful effect ($p < 0.05$). Conversely, *z*-statistics between these values indicate there is no statistically significant difference, meaning the possibility that any observed differences between the pilot population and the total population were due to chance cannot be ruled out.

Index of Multiple Deprivation (IMD)

Eligible pilot population for participating GP practices

The deprivation level within which each participating GP practice (completing one or more screenings) fell was identified through *National General Practice Profiles* (Department of Health and Social Care, 2024) and then converted into an Index of Multiple Deprivation (IMD) score from 1 (most deprived) to 10 (least deprived). For example, if a GP practice was within the '*second most deprived decile*', they were assigned an IMD score of '*2*'. The number of registered one-year-olds in each GP practice involved in the pilot was identified through *patients registered at a GP practice* (NHS Digital, 2024b) to identify a proxy for the total number of children that could be screened within each IMD and GP practice engaging in the CPSS pilot. This was summed for each participating HIN.

Eligible population across all participating HINs

The *English Indices of Deprivation 2019* (Ministry of Housing, Communities & Local Government, 2019) was used to identify the IMD decile in each Lower layer Super Output Area (LSOA). The number of one-year olds in each LSOA was identified through *Estimates by single year of age and sex for 2021 Lower layer Super Output Areas, mid-2022* (Office for National Statistics, 2021b). LSOA codes from 2011 and 2021 were mapped together using *LSOA (2011) to LSOA (2021) to Local Authority District (2022) Exact Fit Lookup for EW (V3)* (Office for National Statistics, 2024). Local authorities were then mapped to HINs using *LSOA (2021) to SICBL to ICB to LAD (April 2023) Lookup in EN* (Office for National Statistics, 2023a). From there, a proxy for the total number of one-year olds living within each IMD decile and HIN could be identified. The proportion of one-year-olds for each IMD decile within GP practices participating in the CPSS in one HIN was compared to that of the proportion of one-year-olds for each IMD decile in the participating HIN overall.

Statistical testing

A binomial statistical test was completed to determine whether the assumed proportion of one-year olds in each IMD decile who could have been screened differed to the corresponding IMD decile in all GP practices in each participating HIN overall.

Assumptions and limitations

- The screening data utilised relied on GP practices filling in and sending their screening data each month, however not all GP practices sent this data each month. This could mean there were omissions in the data.
- It was assumed that there was an equal number of one-year olds across each month of the same year to identify the number of children that could be screened in each GP practice.
- It was assumed that the overall ethnic breakdown of each GP practice engaging in the CPSS pilot identified through *National General Practice Profiles* (Department of Health and Social Care, 2024) was the same as the ethnic breakdown of all one-year-olds at each GP practice engaging in the CPSS pilot.

- Three different methods were used to map local authorities to HINs; there was no lookup available to match local authorities (2021) to local authorities (2023) as identified in *LSOA (2021) to SICBL to ICB to LAD (April 2023) Lookup in EN* (Office for National Statistics, 2023a). The following methods were used and combined to assign each local authority (2021) to a HIN:

  1) Match the local authority code (2021) in *Ethnic group by age and sex in England and Wales* (Office for National Statistics, 2021) to the local authority code (2023) in *SICBL to ICB to LAD (April 2023) Lookup in EN* (Office for National Statistics, 2023a) to identify the ICB, and therefore the HIN.

  2) Match the local authority code (2021) in *Ethnic group by age and sex in England and Wales* (Office for National Statistics, 2021) to the local authority code (2019) in the *English Indices of Deprivation 2019* (Ministry of Housing, Communities & Local Government, 2019). Then, match the LSOA code (2021) to the LSOA code (2021) in *SICBL to ICB to LAD (April 2023) Lookup in EN* (Office for National Statistics, 2023a) to identify the ICB, and therefore the HIN.

  3) Match the local authority name (2021) in *Ethnic group by age and sex in England and Wales* (Office for National Statistics, 2021) to the local authority name (2021) in *SICBL to ICB to LAD (April 2023) Lookup in EN* (Office for National Statistics, 2023a) to identify the ICB, and therefore the HIN.

  - All three HIN mapping outputs were compared against each other, where local authorities with more than one HIN assignment were assessed on an individual basis to identify the most suitable HIN.

- It was assumed that the overall IMD breakdown of each GP practice engaging in the CPSS pilot identified through *National General Practice Profiles* (Department of Health and Social Care, 2024) was the same as the IMD breakdown of all one-year-olds at each GP practice engaging in the CPSS pilot.

2.3. Qualitative analysis

Surveys

Unity Insights created a GP practice staff survey, which was disseminated by Health Innovation NENC to staff members in GP practices who were part of the CPSS. Responses involved a mix of multiple-choice and free-text responses, which were analysed through frequency distributions and thematic analysis.

There were 18 responses to the GP practice staff survey. Overall, 39% (*n* = 7) of surveys were completed by staff in Health Innovation West of England, 17% (*n* = 3) by each of Health Innovation East and Health Innovation North West Coast, and the remainder by Health Innovation West Midlands, Health Innovation Yorkshire and Humber (11%; *n* = 2 respectively), and Health

Innovation North East and North Cumbria (6%; *n* = 1). The survey was primarily completed by practice nurses (44%; *n* = 8; Figure 2), with 11% (*n* = 2) GPs and 6% (*n* = 1) each from other roles such as management and pharmacist roles. This indicates that the sample was representative; practice nurses were some of the most impacted by the CPSS as they were undertaking the patient screening.

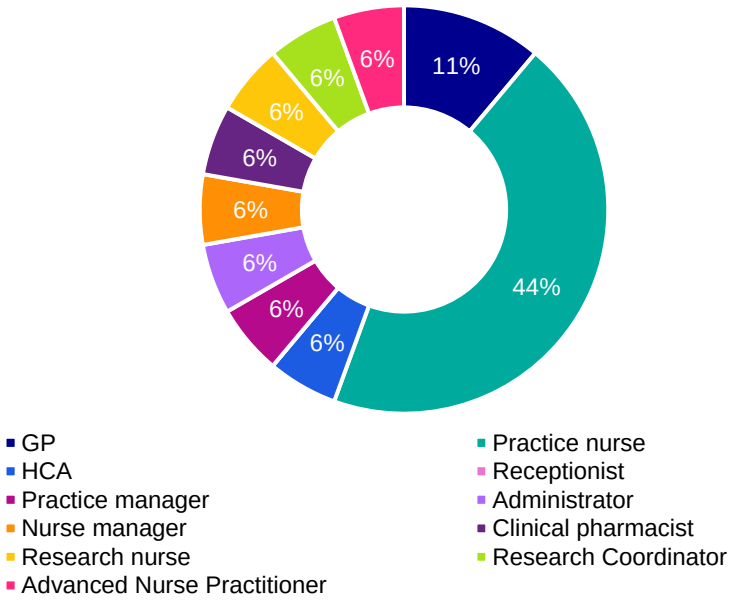


Figure 2: GP practice survey responses to '*what is your role in the GP practice?*' (*n* = 18).

Most staff were involved in managing the CPSS service (56%; *n* = 10; Figure 3), undertaking the tests (50%; *n* = 9), and completing administration tasks (50%; *n* = 9). Just under half of staff (39%; *n* = 7) completed tasks such as identifying and triaging patients, reviewing and actioning patient results and follow-ups, and patient management and clinical oversight. As staff members each fulfilled a number of different roles and there were similar proportions of roles in the survey results, the sample was likely to be representative.

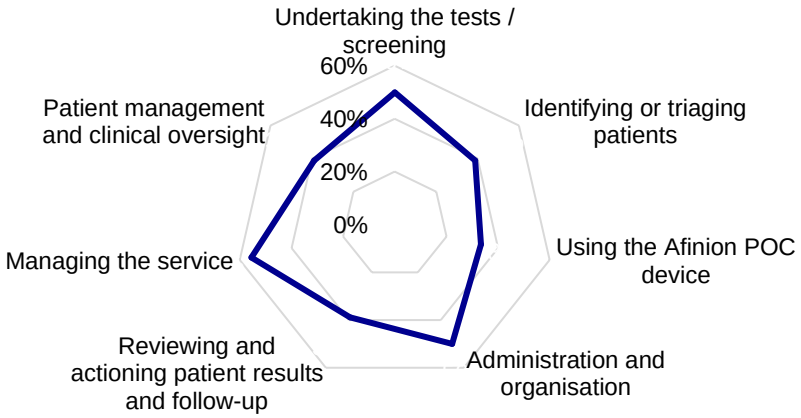


Figure 3: GP practice survey responses to '*what was your role in the child-parent screening service?*' (*n* = 18).

Before Unity Insights began the evaluation into the CPSS, Health Innovation NENC created and distributed surveys to both HCPs who accepted, and who declined the expression of interest (EOI) to implement the CPSS, and to parents who were invited for their child to be screened for FH. The surveys contained a mix of multiple-choice and free-text responses. Unity Insights analysed the survey responses through frequency distributions and thematic analysis. Overall, there were seven respondents in the HCP staff survey who accepted the EOI, 11 respondents in the HCP staff survey who declined the EOI, and 19 respondents to the parent/guardian survey.

Interviews

Semi-structured virtual interviews with GP practice (*n* = 4; two interviewees within GP practices in Health Innovation West of England and one interviewee within GP practices in Health Innovation Kent Surrey Sussex and Health Innovation West Midlands respectively), HIN (*n* = 7; one interviewee from Health Innovation West of England, Health Innovation West Midlands, and Health Innovation North West Coast respectively and two interviewees from Health Innovation Yorkshire and Humber and Health Innovation East respectively), GLH (*n* = 5), an organisation that carried out genetic testing and handled testing for Health Innovation NENC (GENInCode; *n* = 1), and leadership role (*n* = 3) staff members were conducted to understand the staff experience of the CPSS. One semi-structured virtual interview was conducted with a parent whose child completed FH screening, however, did not have an FH diagnosis. Finally, one voluntary, community, and social enterprise (VCSE) interview was also conducted with an organisation who provided input and support to the programme team. Responses were analysed through thematic and semantic analysis to generate themes.

Assumptions and limitations

- Not all staff and parents involved in the CPSS could be surveyed or interviewed, meaning that findings may not be fully representative of the wider population. Despite this, there was a large sample size, so it was assumed that findings were generalisable to the wider population.
- The parent/guardian survey was only completed by those who accepted the FH screening invitation. Therefore, findings may not be reflective of parents/guardians who declined the FH screening invitation.
- No parents of children with an FH diagnosis due to the CPSS agreed to interview, hence feedback from this cohort was unable to be gathered.

3. Results

3.1. Screening data [Q1a; Q3]

Overall, there were 1,820 FH screenings reported as part of the CPSS between November 2021 and October 2024. The 10 GP practices with the most screenings represented 74% of total screenings completed, suggesting that uptake varied considerably between GP practices. This was also reflected within the HINs, where the four (out of seven) HINs with the most screenings represented 87% of total screenings completed.

There was an overall uptake of 27% (weighted average = 27%; median = 11%) across all GP practices that engaged in the CPSS (received the Afinion POC device and completed training). Health Innovation West of England completed the most screenings out of all participating HINs, representing one third of all screenings completed (33%; *n* = 606). Despite this, Health Innovation North West Coast had the greatest average uptake out of all participating HINs (54%; Figure 4). Chopwell Medical Practice in Health Innovation North East and North Cumbria had the highest uptake percentage out of all practices at 133%. Uptake was above 100% in this case as the number of patients eligible for the CPSS per year was assumed to be equal across each month, however Chopwell Medical Practice completed a greater number of screenings (*n* = 5) than the assumed number of eligible patients (*n* = 4 [rounded]). School Lane Surgery in Health Innovation East had the second highest uptake at 75%.

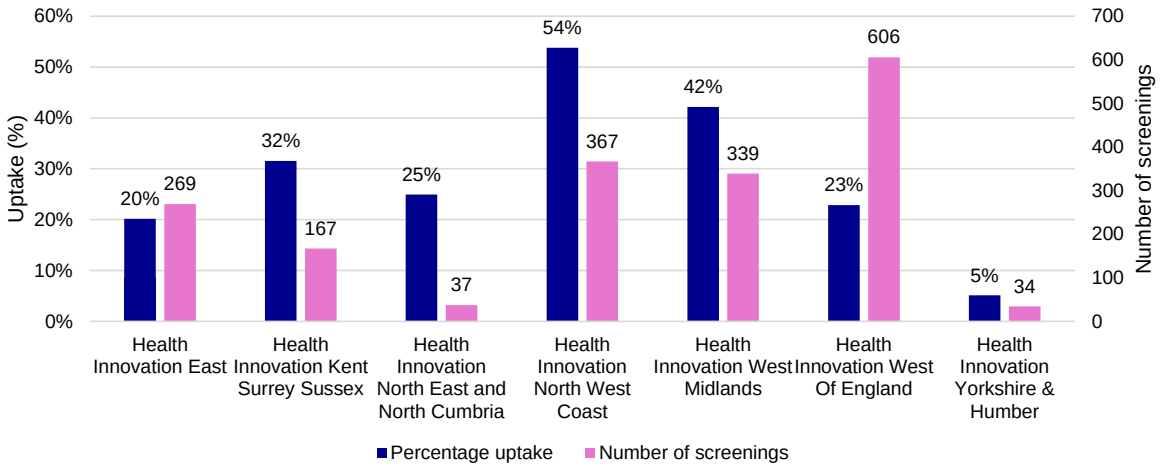


Figure 4: A bar chart highlighting the number of screenings and uptake (%) within GP practices that engaged in the CPSS (received the Afinion POC device and completed training) in each participating HIN. Imperial College Health Partners was excluded from the chart to avoid misinterpretation; there was an uptake of 33%, however only one screening was completed.

Health Innovation West of England completed the most screenings (*n* = 606) and had the greatest number of eligible patients out of all HINs (*n* = 2,652; Figure 5). Further, Imperial College Health Partners completed the least screenings (*n* = 1) and had the lowest number of eligible patients out of all HINs (*n* = 3).

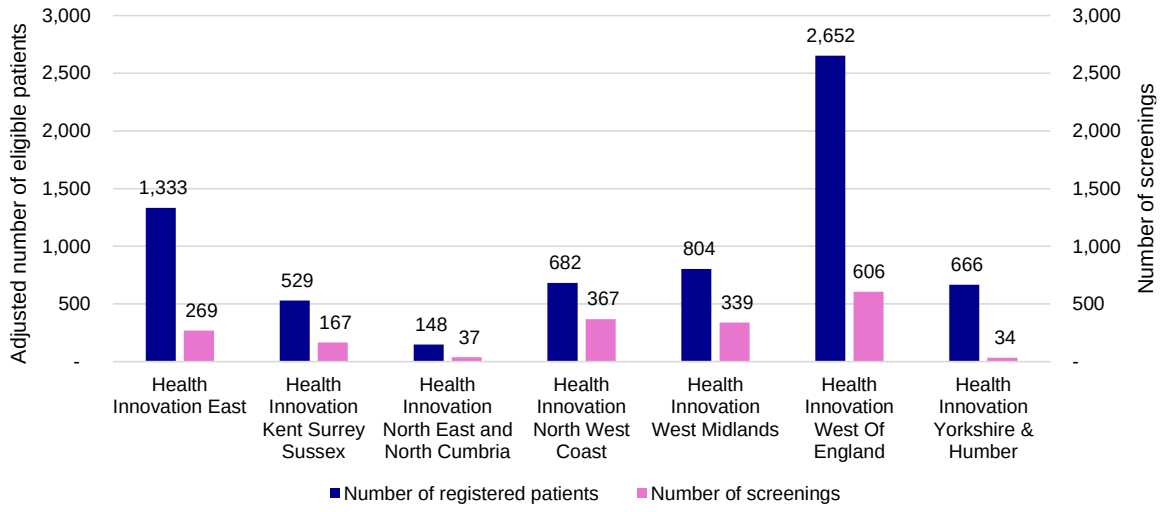


Figure 5: A bar chart highlighting the number of eligible patients and screenings completed within GP practices that engaged in the CPSS (received the Afinion POC device and completed training) in each participating HIN. Imperial College Health Partners was excluded from the chart to avoid misinterpretation; there was an uptake of 33%, however only one screening was completed.

Within the dataset, there were 20 out of the 67 total GP practices examined that received training and the Afinion POC device, but did not complete any screenings (Health Innovation East *n* = 4; Health Innovation NENC *n* = 3; Health Innovation North West Coast *n* = 1; Health Innovation West Midlands *n* = 3; Health Innovation West of England *n* = 5; Health Innovation Yorkshire and Humber *n* = 4). Figure 6 highlights the change in overall uptake for each HIN when excluding GP practices with 0% uptake.

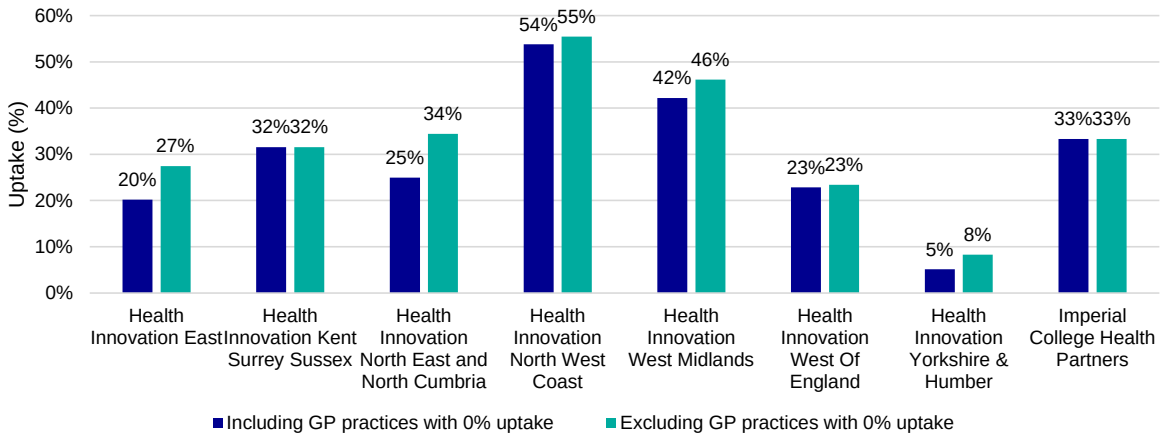


Figure 6: A bar chart highlighting uptake figures for each HIN when GP practices that received training and kept the Afinion POC device but completed no screenings were included and excluded from the analysis.

All seven GLHs in England supported the CPSS pilot, undertaking 81 genomic tests in total. Further, 73% (n = 59) of these tests were completed in two GLHs (North West and South West). Overall, there were two diagnoses of FH out of all 1,820 child screenings completed (0.11%). This was lower than that of the study in Wald et al. (2016), which identified 20 diagnoses of FH in 10,095 child screenings using a similar pathway (0.20%).

A fisher's exact test was performed to compare the true number of FH diagnoses out of the total population screened against the expected from (Wald et al., 2016). The Fisher exact test statistic value was p = 0.5628, which was similar to Chi-square statistical findings, indicating there was no statistically significant difference between findings from the pilot and Wald et al. (2016; $p < 0.05$). This did not confirm that the findings from the study and pilot are identical, but suggests insufficient evidence to conclude a meaningful difference, or that any observed difference was not purely due to chance. Statistical power was calculated to estimate the sample size required for the pilot study to achieve similar statistical power as Wald et al (2016). It was determined that 16,459 screenings would be needed to detect a difference of 0.09%, if one exists, with the same level of statistical confidence.

Health inequalities

Ethnicity

Binomial statistical testing revealed the proportion of Asian (6% versus 11%), Black (2% versus 3%), Mixed or multiple (2% versus 7%), and other (1% versus 2%) ethnic groups was statistically significantly lower when comparing the eligible CPSS population with the overall eligible population across all participating HINs ($p < 0.05$; Figure 7). The proportion of White individuals engaging in the CPSS pilot was statistically significantly higher than the overall eligible population across all participating HINs (88% versus 77%). This suggests that the CPSS may exacerbate health inequalities in relation to ethnicity.

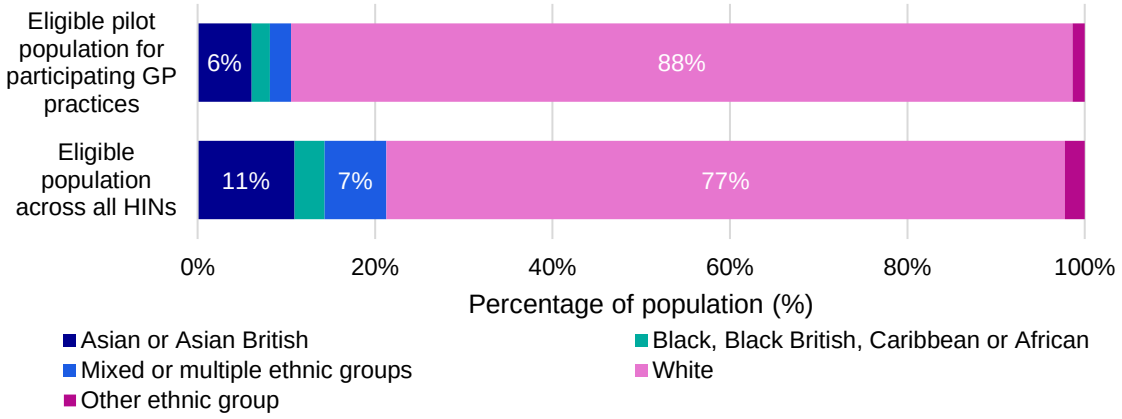


Figure 7: Ethnicity breakdown of the total eligible screening population in GP practices that participated in the CPSS and the total eligible screening population across all participating HINs.

Deprivation

Binomial statistical testing suggested that the CPSS was statistically significantly less representative of people living in areas of IMD deciles 1, 2, 3, 6, and 8 and statistically significantly more representative of people living in areas of IMD deciles 5, 7, and 9 ($p < 0.05$; Figure 8). The CPSS yielded no statistically significant difference of people living in areas of IMD deciles 4 and 10 when comparing to the total eligible population across all HINs ($p < 0.05$). The Core20 population represents the most deprived 20% of the population: individuals living in an area of IMD decile of 1 or 2 (NHS England, 2021). When examining decile scores of 1 and 2, the CPSS was statistically significantly less representative of those living in an area of IMD of 1 or 2 (Core20; 25% versus 14%). This suggests that the CPSS exacerbated health inequalities in relation to deprivation.

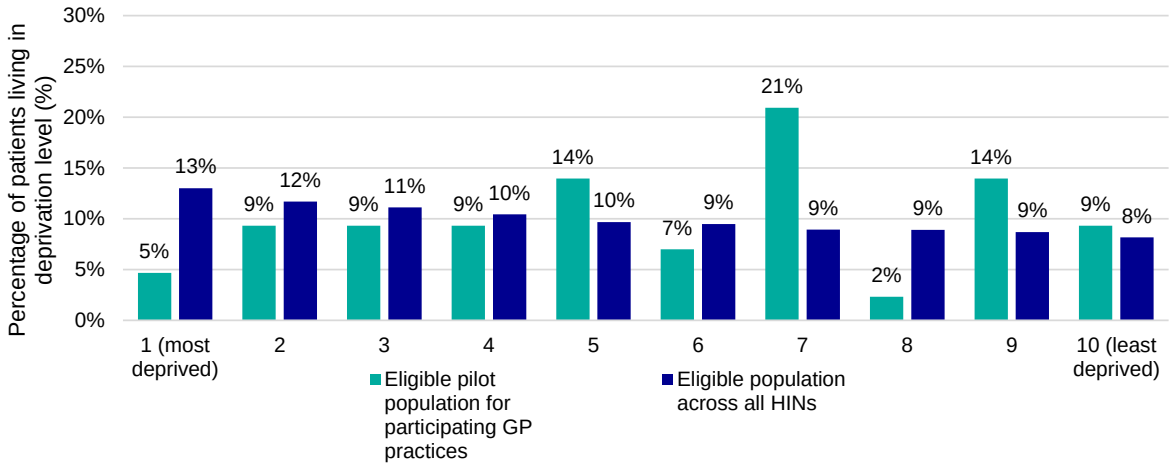


Figure 8: IMD breakdown of the total eligible screening population in GP practices that participated in the CPSS and the total eligible screening population across all participating HINs.

3.2. How the CPSS was implemented [Q1b]

GP practice implementation

Interviewees highlighted that GP practices were typically approached either by Health Innovation NENC or their local HIN and were informed and invited to the CPSS before deciding whether to implement the service. GP practices that agreed to implement the CPSS were sent the implementation manual and resources (such as the Afinion POC device) to allow the CPSS to be completed. During interviews, staff noted they generally found the implementation manual useful and would refer back to this when required. Staff from all four GP practices highlighted that they did not need to adapt the contents of the implementation manual to their specific GP practice needs, with one staff member not being aware of the manual. Nurses were trained on how to complete heel prick tests and how to use the Afinion POC device. It was noted that GP practices could withdraw from the CPSS at any point; in such cases, the Afinion POC device provided was returned to Abbott. At the conclusion of the CPSS, GP practices that remained engaged were gifted the device by Abbott. GP practices also joined the CPSS at differing times.

Screening was typically completed during the child's one year immunisation appointment, noted within GP practice staff interviews. Some GP practices held immunisation clinics on set days of the week, where several appointments were completed. HCP interviewees invited parents to complete the screening appointment in several different ways, such as text messages or letters, which usually included information regarding the importance of screening and what to expect during the screening appointment. This was also echoed in the staff survey, where most parents were invited to the screening via a surgery letter (71%), however almost a third of parents were invited by child health information service (CHIS) letter, texts, or telephone calls respectively (29%; Figure 9). In contrast, all parents/guardians in their respective survey noted they were invited to the screening in person (*n* = 10).

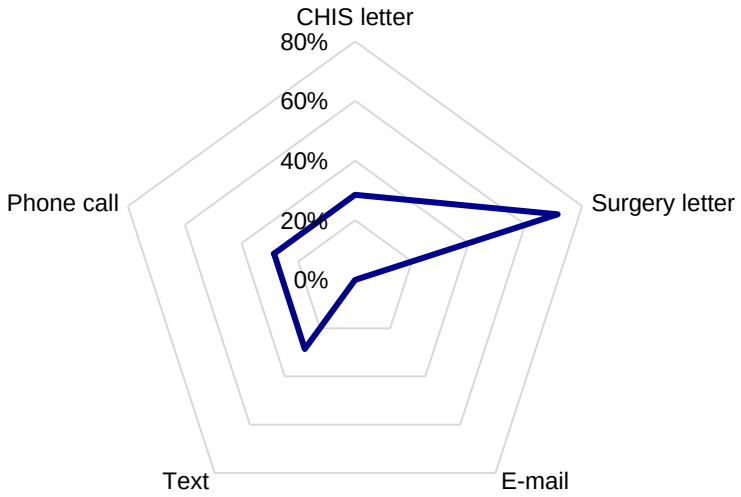


Figure 9: Survey responses to the question '*how did you invite parents for screening?*' (*n* = 7).

Should the parent accept the screening invitation, their immunisation and screening appointment was either the same length as the original immunisation appointment or doubled in length (10 minutes longer), depending on the GP practice. Survey findings indicated that five out of seven staff (71%) extended their immunisation appointment times to accommodate the screening. Further, three out of seven surveyed staff (43%) did not increase healthcare personnel capacity in the immunisation clinic.

The FH screening involved a heel prick test, which was completed either before or after the immunisations. One staff member noted that they could complete three immunisation appointments including FH screening in one hour. There was variation in the number of screenings completed each month. Staff suggested that this was due to fluctuations in the number of babies attending appointments, staff absences (while four staff members were available, two were required per session to run the clinic), natural variation, and the prioritisation of smaller babies (eight-month-olds were given priority over one-year-olds).

HIN implementation

There was a national call during CPSS implementation to introduce GP practices to the CPSS in effort to foster interest. Health Innovation NENC liaised with HINs to identify GP practices who wanted to engage with the CPSS and facilitated rollout, training, and provision of materials. HINs decided whether they could support GP practices who were offered an EOI to engage with the CPSS. If the HIN staff member supporting the GP practice had existing contacts within the GP practice, the GP practice staff were more likely to engage with the CPSS. Interest varied across HINs, for example, in Health Innovation North West Coast, GP practices in one ICB were more responsive, however GP practices in another were less receptive.

Once signed up, HINs worked with GP practices to ensure they understood the information (such as the implementation manual) provided and supported with implementation. Three out of the six HIN interviewees noted that they did not change the implementation manual. Here, they highlighted the manual was useful, thorough, and contained everything the GP practice required. In contrast, one HIN interviewee thought the manual was generic and would have liked more tailored support on specific challenges they may face. One HIN interviewee adapted the manual as they had a regional FH service and wanted to keep them informed. This HIN adapted the process by meeting with the regional FH service regularly to ensure both services fed into each other. One HIN interviewee was unsure if GP practice staff had read the manual.

Following implementation and after the impact of COVID-19 had lessened, some HINs reopened advertisement for the CPSS, however it was noted that there was difficulty identifying which GP practices to target. One HIN interviewee noted that they asked GP practices they regularly worked with, advertised in newsletters, and asked research nurses, however, did not receive any responses. They noted this was likely due to the after effects of the COVID-19 pandemic.

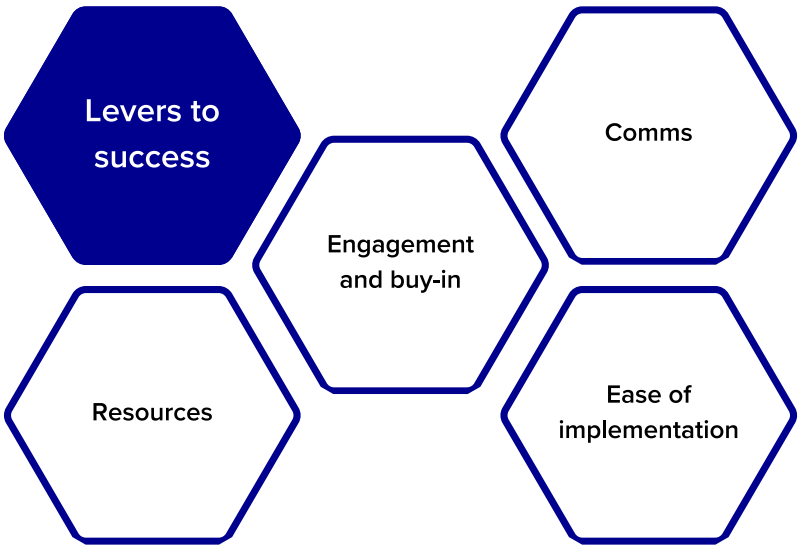
GLH implementation

There were 81 genomics tests in total during the CPSS pilot. GLH staff were informed by a clinical partner about implementation of the CPSS. Adjustments were made to the standard genomic

screening process to accommodate the CPSS pathway, primarily due to the smaller sample size of the test (240 microlitres of blood per test, much less than typically received), which extended the duration of DNA extraction. Some samples arrived in broken glass specimen tubes, presenting additional challenges for extraction. The robotics used for extraction were adapted to accommodate the height of the test tubes received. One GLH interviewee noted they had not previously conducted capillary blood extractions and highlighted the importance of ensuring sufficient DNA extraction. There was a smaller number of tests to complete compared to other pathways, which one GLH staff member noted to be "*not a difficult amount of work*".

A variant of uncertain significance (VUS) is a change in a gene's DNA sequence that has an unknown effect on a person's health. A polygenic risk score (PRS) is an estimate of an individual's genetic risk for a trait. When completing the test reports for the replication of the Wald et al. (2016) study, GLHs were instructed not to report VUS and PRS, despite typically reporting them in other pathways.

3.3. Levers to success [Q1b; Q2a]



Engagement and buy-in

Engagement from staff was noted as a facilitator of the CPSS by one GP practice, five HIN, and three leadership role interviewees, and one GP practice staff survey respondent. One GP practice staff member suggested that inviting GP practices to implement the CPSS must be completed by a clinical leader known to the GP practice. Further, a leadership role interviewee suggested the importance of engaging with those who are already invested, such as CVD leads, individuals with FH, or individuals who knew someone with FH. Once signed up, enthusiastic staff members were noted to be key in proactively driving GP practice buy-in due to their enthusiasm and existing

contacts within their respective GP practices. Having an enthusiastic GP practice lead was linked with greater uptake. Therefore, individuals who are known to the GP practice and enthusiastic about the prospect of the CPSS should be selected to invite GP practices to participate in the service.

Although the initial incentive of paying the GP practice £3 for every screening was not satisfactory, two HIN staff and the VCSE interviewee considered the financial incentive a facilitator of the CPSS following the increase to £10 per screening. One HIN staff member noted that any money going into GP practices is positive, however the size of the financial incentive may not be the sole reason they enrolled in the CPSS, and that staff member questioned the size of the incentive in relation to the additional work required by the GP practice.

System support was also highlighted as a facilitator of buy-in to the CPSS by two HIN interviewees and one leadership role interviewee. Support from other HINs was noted to help with generating ideas to encourage engagement, share learnings and barriers, and reassure HIN staff they are not alone. Communities of practice were also noted as facilitators. One HIN interviewee highlighted their first meeting involved a presentation from a staff member in a high performing GP practice who detailed their process, which was found to be beneficial for newer GP practices. Nationally recorded Microsoft Teams meetings were also held for GP practices during implementation to highlight why the CPSS was being conducted and the previous study the work came from. A nurse who was influential in screening children in Wald et al. (2016) and a patient from the previous study told their experiences. This gave first-hand insight to GP practice staff members to help encourage engagement and buy-in to the CPSS. A local lipid expert also joined initial meetings for the CPSS and was able to answer any questions GP practice staff had, with answers being tailored to their specific region.

Parent uptake was noted as a significant lever to successful implementation of the CPSS by GP practice staff survey respondents and GP practice staff interviewees. One survey respondent from a GP practice with 35% uptake (higher than the average uptake of 27%) noted that phoning parents and booking them in for the FH screening directly meant parents did not have to book the appointment themselves, facilitating parental uptake. Ensuring the parent had read the information before the screening was noted by an interviewee to facilitate buy-in as this ensured they understood the intentions of the CPSS.

HCPs were asked within the HCP staff survey what they considered to be the main reasons for parents agreeing to have their child screened for FH. Here, five HCPs suggested the importance of diagnosis. Two HCPs respectively suggested that parents may accept due to the efficiency of the procedure or due to a family history of high cholesterol. In the parent/guardian survey, 100% (n = 19) of respondents felt they were provided with enough information about the FH screening and would accept the FH screening invitation again for another child. When asked if there was anything that influenced their decision, or what other information would have been useful, two parents highlighted that the importance of diagnosis influenced their decision.

"the fact that [the CPSS] could highlight the condition in all family members or their children and give them the opportunity to take preventative measures"

- *Parent/guardian survey respondent*

One parent noted previous heart problems influenced their decision to participate, whilst two parents highlighted explanations of the procedure from a nurse (*n* = 1) or in the leaflet (*n* = 1) to be useful.

One GP staff interviewee noted they had not had many parents decline the invitation and considered screening to be well-received. Further, they noted that children were not "*bothered*" by the test, suggesting the test was accepted by children.

Communication

One HIN staff interviewee suggested that uptake starts with the receptionist as they must be able to "*sell*" the CPSS to the parent. One GP practice staff interviewee highlighted they updated their website to ensure both staff and parents could view the benefits of engaging in the CPSS. Their engagement communications were released via the local GP Federation (a group of GP practices working together to form a single organisational entity) as these were considered a trusted source to GP practice staff.

Ease of implementation

For sites with greater resource, evidenced through GLHs that could manage a large volume of tests or GP practices that completed a large volume of screenings, ease of implementation was noted as an enabler. GLH interviewees noted that the CPSS slotted easily into their existing service, making implementation easy. The CPSS was noted to be well organised and the preparation for implementation occurred ahead of the go-live date, which facilitated implementation. One GLH interviewee noted that their GLH was large, which meant they already had the expertise and resources required to yield the desired result, which further helped implementation. Finally, an interviewee in a GP practice that handled a high volume of screenings highlighted that implementation was easy due to the instructions provided. Here, they noted that the CPSS slotted into their practice easily as they did not need to set up an entirely new pathway.

Resources

Six out of seven HCP staff survey respondents felt well equipped to implement the CPSS in terms of training and support, with all seven respondents noting there was a satisfactory range of patient support materials available. Interviewees noted the resources provided such as the standard operating procedure (SOP) and report templates were useful. One GP practice interviewee noted that the information was well explained. A HIN interviewee highlighted that the manual templates, referral forms, and SOPs were useful, and the FAQ section was well received. This was echoed in

the staff survey where five out of seven (71%) HCPs found the resources available on FutureNHS useful as guidance. When asked to expand on their answer, only HCPs who reported they found the guidance useful explained why. One HCP reported the guidance provided was "*easy to understand*". Another HCP highlighted that the "*training and information was excellen*t", whilst another highlighted that the CPSS manual was "*useful*", but "*have not looked at anything on Future NHS [sic]*". Finally, one HCP suggested that "*information on quality controls could be better identified, especially lifespan on an opened Quality control solution. Always takes me a while to find it and end up finding the info [sic] from the leaflet inside the box*". Finally, GLH interviewees also noted that the SOP and report templates were useful.

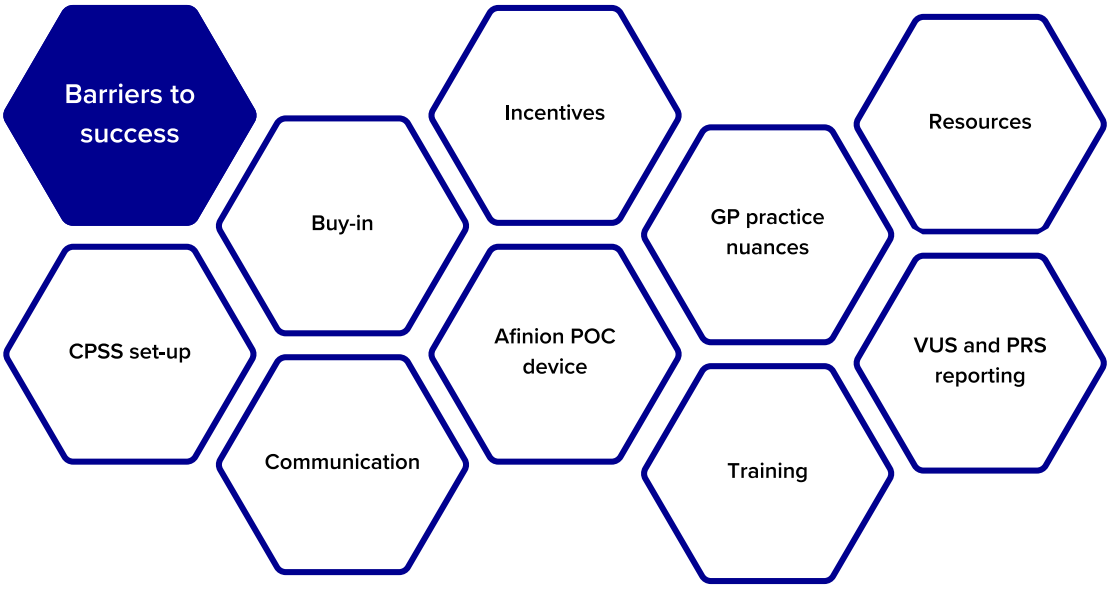
One GP practice interviewee had no issue ordering in the cassettes. The training was noted to be sufficient and straight forward and one HIN interviewee highlighted they found it beneficial to train staff who had never used the Afinion POC device as this helped to avoid excluding GP practices based on this. In the GP practice staff survey, 72% (*n* = 13) of staff agreed there was an appropriate amount of training provided to enable them to complete their role within the CPSS. Of the three HCPs who disagreed (two practice nurses and one research nurse), all three staff noted the need for additional training on wider aspects of the pathway to ensure there was clarity from identification and screening to ongoing management and support of patients, with one staff member suggesting the need for face-to-face training. Most surveyed staff found the Afinion POC device easy to use (76%; *n* = 13), however three staff members (a GP, a practice nurse, and a research nurse) found the device difficult to use. When asked to expand, staff noted that taking the sample was difficult due to errors, for example the test could not be read if it was inserted the wrong way around and they would have to start again if this happened. One staff member noted that "*fitting in calibration for the nursing team and obtaining consumables*" made using the Afinion POC device difficult.

"don't think anything more could have been provided to make implementation easier"

- *GLH staff interviewee*

Screenings were almost always completed in the immunisation appointment by a practice nurse. One GP practice interviewee highlighted that they completed the screening before the immunisations to allow the test to run through the Afinion POC device, ensuring they still had the time to complete the immunisations within the allotted time. At this GP practice, they doubled the appointment length to 20 minutes, however the extra 10 minutes was not always needed. Another GP practice interviewee noted they hosted their immunisation appointments on the same two days each week. This was thought to have made nurses telling parents the days of appointments in person, via text, and email much easier, making them more likely to highlight and encourage screening uptake.

3.4. Barriers to success [Q2a; Q2b]



Please see 'Appendix B: Interviewee suggestions to improve the service [Q2b]' for interviewee recommendations on how the CPSS could be improved and their perceptions on the future of the CPSS. These recommendations have been incorporated and accounted for where relevant against the wider breadth of evidence generated in Section 5.

CPSS set-up

The CPSS was intended to go live at the same time as the lipids and FH programme in October 2020 but was delayed due to the COVID pandemic. HIN and VCSE interviewees noted that this timing hindered provision of the CPSS as NHS staff prioritised COVID-19 vaccinations over screening services. Therefore, the timing of CPSS implementation within GP practices may have had a negative impact on the success of the screening service.

"primary care was stripped back and were trying to introduce something new, which was hard"

- *HIN staff interviewee*

Interviewees found some procedural elements of the CPSS difficult. For example, one GP practice interviewee faced difficulties deciding how long was required for the appointment and another GP practice interviewee thought the test required two staff members (one to hold the child and the

other to complete the heel prick test), however the previous study did not require two staff members.

Within HCP staff survey respondents who declined the CPSS invitation, staff capacity was the largest factor that influenced their decision to not participate (91%; *n* = 10; Figure 10). Further, seven out of eleven HCP staff suggested improving time availability to improve uptake of the CPSS. GP practice and HIN interviewees also noted difficulties with staff capacity. Further, HIN interviewees noted issues with capacity. If there was only one nurse in a GP practice completing the screening and they left the GP practice, no screenings were completed once the nurse left. It was noted that screening numbers reduced due to this, particularly within smaller GP practices. HINs with larger GP practice uptake faced difficulty handling multiple ICSs engaged with the CPSS due to capacity. Data collection, such as recording the number of screenings completed, was also highlighted to be an additional administrative burden on GP practices, noted by a HIN interviewee.

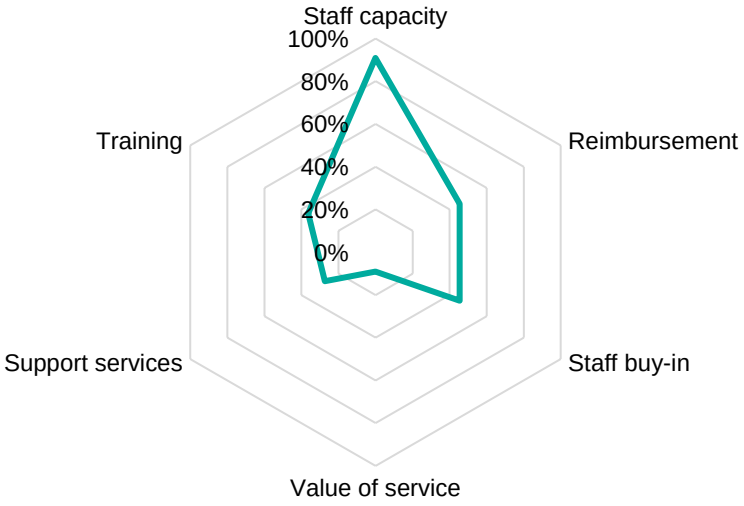


Figure 10: HCP staff declined invitation survey responses to '*What were the factors that influenced your decision not to take part in the Child-Parent Screening Service (please tick all that apply)?*'.

GLHs noted few difficulties with pathway setup, however, did identify that setting up the extraction method was difficult at first due to the change in format of the tests. Despite this, it was noted that the screening tests did fit into their existing pathway with time.

Lack of staff and parent buy-in

Although noted as a benefit to CPSS implementation, staff from GP practices, HINs, and leadership roles also raised staff buy-in at varying levels as a factor that hindered provision of the CPSS. HIN interviewees reported difficulty trying to encourage ICS-level buy-in, where some were more engaged than others. One HIN interviewee noted that they were surprised at the lack of

interest as they thought the CPSS would be an "*easy sell*". In contrast, another HIN interviewee suggested that obtaining buy-in with a lack of evidence was challenging; 1 in 250 were found to have FH in previous literature, however at the time the pilot had tested 1,000 people and only found one patient with FH. HIN interviewees tried to get the message out to GP practices in various ways such as through comms and webinars, however no method appeared more effective than others. Engagement was higher from GP practices with a lead who was more engaged with the screening, however when these leads left, uptake often slowed down. This emphasised the importance of an enthusiastic driver in implementation of the CPSS.

GP practice, HIN, and leadership role interviewees also highlighted a lack of GP practice buy-in. GP practice staff were suggested to be reluctant due to capacity issues. One GP practice staff member noted that trying to convince staff to complete the screening in a 20-minute appointment was difficult. One HIN interviewee also suggested that there may be concerns about whether nurses felt able to answer questions about FH that parents may ask. Further, one HIN interviewee highlighted that there was "*nervousness*" around completing the heel prick tests; this was a new procedure for staff. It was suggested that a live video, instead of an animation offered during training, would have helped. These findings highlight the importance of high quality training and engagement for all staff members.

"wider treatment room team were not engaged… we were not successful"

- *GP practice survey respondent*

GP practice staff were suggested to be hesitant to buy-in to the CPSS due to a perception that parents will push back against the screening service. It was highlighted that some parents may not like the thought of their baby being injected four times (vaccinations) and then having a heel prick test (screening). Nurses assuming that parents would decline the test was suggested to be a hinderance to implementation of the CPSS due to reluctancy to invite parents to complete the screening.

One leadership role interviewee identified that responsibility for achieving the 25% target stated in the NHS *Long Term Plan* (n.d.) for FH had not been delegated to a specific organisation or clinical specialty (either genomic medicine or CVD). This meant that there was no ownership to drive the CPSS forward and encourage other teams to complete the screening process. Hence, the CPSS relied on those who had a motivated interest in FH to encourage screening uptake.

Although parent engagement was noted as a lever to success, lack of parent engagement was also noted as a barrier to successful implementation of the CPSS. There was a low number of eligible children for the test in some cases (such as within rural practices), which then led to a lower number of parents accepting the invitation.

Parents were suggested to reject the invitation for several reasons such as the requirement to travel to the appointment, a lack of education surrounding FH, and inflicting more pain on their child during their already stressful immunisation appointment. HCP survey respondents noted that parents may decline the invite due to the potential "*trauma*" to the child caused by an additional skin puncture. Staff GP survey respondents highlighted the need for parent education on the importance of FH screening to encourage uptake.

"not wanting their child to have an additional injection to the 4 they have at imms"

- *HCP survey respondent who participated in the CPSS*

A staff member noted that in their GP practice, they assigned parents an appointment date and time for the screening and immunisations and asked the parent during the appointment if they were willing for their child to be screened. This allowed parents to become educated on the importance of FH testing and ask any questions before deciding whether to have the test. The staff member highlighted that this yielded greater uptake compared to their previous method of letter invitations.

One staff survey respondent suggested raising awareness of FH using social media. Another highlighted that they felt the patient information leaflet was misleading when noting that the test was "*well tolerated*". They suggested this should be updated as they did not consider this to be the case in their experience.

Communication

Interviewees noted variation in communication across different areas of the pathway. GP practices did not always know who to contact for troubleshooting advice. For example, one GP practice interviewee noted that they asked for advice when a child was on the border for high cholesterol levels, however they did not receive a response. Further, some GP practices did not make their respective HIN aware that they had not received their training or equipment. This meant that screening could have started much earlier if the HIN were aware. Finally, when GP practices were completing screening tests, one interviewee suggested that although parents agreed to the screening, it was not always clear if they were aware what they were agreeing to. This suggests the need for further parent-staff communication to ensure the parent understands why their child is being screened for FH and what this consists of. One HIN interviewee noted that the lead HIN and POC device supplier were heavily involved at the start of implementation, however communication waned once GP practices were onboard. They suggested that the lines may have been blurred in the roles of the two organisations and there was need to have better designated roles and responsibilities, and that these should be conveyed to GP practices to help with communication. This highlights the need for roles and responsibilities to be defined and included in the implementation manual.

One GLH interviewee noted that paperwork was not always filled in on the screening tests, including the patient's NHS number, postcode, or GP practice name. This meant that some screening tests were hard to trace. The interviewee noted that they created a template email to explain the error to GPs, which they highlighted to be useful. Further, the GLH staff interviewee also suggested that it was not always clear where the test reports should be sent to due to lack of communication.

Incentives

Interviewees questioned whether the incentives of the CPSS facilitated GP practice uptake. It was noted that the financial incentive was too low at the start, offering £3 per screening completed or £5.50 if a GP practice already had their own Afinion POC device. When increased to £10 per screening, the incentive was noted to be more attractive to some GP practices, however others remained indifferent. HCP staff survey respondents were asked what they would suggest changing to improve CPSS uptake. Here, two out of eleven respondents noted the incentives.

Afinion POC device

The Afinion POC device was intended to be an incentive in two respects. Firstly, the devices were provided free of charge, so that, subject to external purchasing of consumables, the devices could be used for a range of other testing and diagnostic procedures. Secondly, rather than needing to purchase or return the devices at the end of the pilot, it was agreed that the practices would be allowed to keep them. Despite this, the machines were not perceived to be a large incentive for GP practices to engage with the CPSS due to both lack of awareness around alternative uses, and the cost of consumables. Additionally, interviewees reported that some staff asked to return the device.

Taking the sample itself was noted to be time consuming by GP practice survey respondents. The kit had to be thawed, which took approximately 30 minutes, and the kit could not be re-chilled. Staff time was also limited outside of sample collection, where some GP practices faced difficulty finding time to train staff for the CPSS. This led to less screening being completed due to a delayed start.

GP practice interviewees and survey respondents noted that the Afinion POC device would yield errors. It was suggested this could be due to several reasons, such as the cartridge being too cold, an air bubble in the sample, putting the sample in the wrong way around, and a lack of practice. This led to the sample having to be collected again, where some parents would reject the second test due to the pain caused to the baby. One interviewee suggested there was one error in every four tests, and another suggested one in every six tests, suggesting this was a prevalent issue. One GP practice interviewee questioned the reliability of the test; the results were often different to the follow-up results from the GLH. One GP practice survey respondent suggested that the tests should be completed in batches led at a PCN-level due to the errors.

GP practice nuances

Some GP practices were in rural, isolated areas with an older population. One HIN interviewee noted that smaller village GP practices had lower screening numbers, leading to lower uptake.

Training

Interviewees noted that the training provided lacked clarity in some areas. For example, the training video provided was an animation, whereas interviewees suggested they would value a live video or in person training more. Further, some nurses thought they required assistance from an HCA or another nurse to complete the screening, however according to one HIN interviewee this was not required. This resulted in more nurse time being allocated than necessary to complete the screening, reducing GP practice engagement. Some GP practice staff were "*nervous*" to start using the machine, however, found this dissipated once they became accustomed to using the machine. In the HCP staff survey, one respondent suggested the need for "*more training on how to obtain the samples to be sent off to the lab*."

Resources

One leadership role interviewee noted they had to stop recruiting GP practices at one stage due to a worldwide shortage of lipid panels for the Afinion POC device (used to identify abnormalities in blood lipid concentrations, such as high cholesterol levels). This shortage ran from mid-July 2023 to early September 2023 and resulted in several GP practices cancelling screenings, with eight new GP practices that were due to being onboarded being delayed.

One GP practice interviewee highlighted that they ran out of heel prick tests so began to use finger prick tests, however they were difficult to draw blood from. This GP practice did not receive any heel prick tests for the CPSS despite being told that they would, and the GP practice struggled to find and order them as they were sold out. This resulted in resourcing issues, which led to difficulty completing screenings. Upon discussion with a leadership role interviewee regarding the lack of heel prick tests, it was raised that there were still heel prick tests available for the CPSS. This suggests that the signposting to where the tests can be obtained should be improved within the implementation manual.

VUS and PRS reporting

GLH staff were advised not to report any VUS or PRS in the CPSS, however this typically was reported in other pathways. One interviewee noted that a patient not receiving a VUS in their report meant that there were known variants not being reported, which the interviewee perceived as inappropriate. They noted there was an uncertainty element and understood that VUS reporting could lead to misinterpretation, however, were concerned if someone read the report further down the line, saw no VUS, that they would assume there was no problem. Another interviewee noted that GLHs should be able to report that they have found a variant that could be of interest; it could be that in a year or two, further information may come to light, which may make the VUS result more useful. The interviewee suggested there should be a feedback mechanism in place to feed this back to the family.

4. Discussion

A summary of the discussion is as follows:

- The most optimal implementation strategies revolved around communication and buy-in, where having whole site staff buy-in and ensuring communication across all sites was key to yielding high screening uptake levels and therefore pathway success.
- The main lessons learned from implementation were:
    - Staff and parent buy-in is essential for high uptake
    - Clear communication between all sites is essential for smooth implementation
    - Staff must see the value of the incentives to buy-in to the CPSS
    - Staff were satisfied with the training provided
- The CPSS demonstrated potential in advancing the NHS *Long Term Plan*'s (n.d.) ambitions; the findings from the pilot were similar to Wald et al. (2016). By identifying FH cases early, the CPSS facilitates timely interventions, such as lifestyle advice and cholesterol-lowering medication, significantly lowering the risk of myocardial infarction and strokes.

4.1. Pathway success [Q1]

The current pilot identified two FH diagnoses out of 1,820 screenings completed. Pilot diagnosis rates of FH in children (0.11%) were much lower than Martin et al. (2022), which yielded a diagnosis rate of 0.67% in 448 children in Australia. It is estimated that 1 in 300 people have FH in Australia, of which 80% have not been diagnosed, yielding similar estimated prevalence rates to the UK (FH Australasia Network, 2025). Diagnosis rates within Martin et al. (2022) were much higher than the estimated prevalence in Australia. Despite this, the percentage diagnosed in Martin et al. (2022) may not accurately reflect the national prevalence rates due to the small population screened. Further, diagnosis rates in the current pilot may have differed to Martin et al. (2022) due to differences in diagnostic criteria, where the current pilot may have used more sensitive genetic testing, for example.

Wald et al. (2016) identified 20 FH cases (diagnosed through identifying an FH mutation through DNA sequencing and one high cholesterol level reading) out of 10,095 child screenings completed (0.20%). In the current pilot, 1,820 screenings were completed, and 2 FH diagnoses were identified (0.11%), yielding a lower diagnosis rate. There was no statistically significant difference in diagnoses rates when comparing findings from Wald et al. (2016) to the current pilot, indicating that any differences observed could not be ruled out as due to chance at the 95% confidence level. The case detection rate was approximately half of the previous study (0.11% compared to 0.20%), however, statistical tests (Fisher's exact test and statistical power testing) were insufficiently powered to detect a statistically significant difference between these values. To reach a diagnosis

rate of 0.20% or higher, the pilot would have had to diagnose FH in two more children (3.64 diagnoses required to reach a diagnosis rate of 0.20%).

There may be a difference between diagnoses rates in the pilot and in Wald et al. (2016) due to several reasons. Firstly, Wald et al. (2016) had a greater sample size than the current pilot, meaning findings may be more statistically robust and less susceptible to random variation, whereas the smaller sample size in the current pilot may lead to greater variability in diagnosis rates.

Secondly, differences in demographic factors may impact results. Even though FH is not currently known to be related to a specific ethnicity for example, as the condition is genetic, there may be localities with a slightly greater prevalence. Wald et al. (2016) did not specify the areas of the UK that the screenings occurred within, so this was unable to be compared.

Finally, the screening method of measuring cholesterol levels once and then completing DNA sequencing may yield false negatives. This is possible as FH can be diagnosed through two high cholesterol readings within three months. Patients with an initial high cholesterol level reading but no genetic FH must complete a subsequent cholesterol test to determine whether they have an FH diagnosis. The Family Heart Foundation suggests that 30% to 40% of people with FH may test negative during genetic testing due to false negatives, having a mutation not yet identified to be pathogenic, or having a variant in a gene not currently identified to be related to FH (Seim, 2025). Lifestyle choices, such as already eating a healthy diet, may also yield cholesterol levels in line with an individual without FH and lead to FH going undetected.

As many as 16,459 screenings were needed to be completed to achieve an 80% probability of detecting a statistically significant difference if one existed. This highlights the need for more screenings to have occurred to understand whether the pilot and Wald et al. (2016) findings significantly differed. Results indicate the pilot diagnoses rates were not statistically significantly different from the expected diagnoses figures from Wald et al. (2016), due primarily to sample size limitations in the pilot. Further testing and continuous monitoring are required to strengthen the evidence if broader implementation occurs.

The number of screenings completed (*n* = 1,820) was lower than the number of screenings ambitioned (*n* = 5,000). An understanding of how the ambitioned number of screenings was calculated should be sought. For example, the ambitioned number of screenings may be based on a much larger number of GP practices implementing the CPSS and yielding consistently high screenings. Further, the ambitioned number of screenings may not have accounted for external factors that the CPSS was unable to control, such as recovery from COVID-19 and a worldwide shortage of reagents. Regardless, findings from qualitative analysis suggest that there was room for improvement in the number of screenings completed, suggesting this estimation may be achievable in the future.

The success of the CPSS was directly dependent on the number of FH screenings completed in the pilot sites. The likelihood of a GP practice agreeing to complete FH screenings was typically increased if the staff member inviting the GP practice was known by GP practice staff. One HIN interviewee thought the CPSS would be an “*easy sell*,” but no GP practices from the region

expressed interest when first asked. The lack of staff buy-in continued when implementing the CPSS, where this HIN had one of the lowest uptakes out of all the HINs engaging in the CPSS (Figure 4).

Ensuring ICB-level support for GP practices may lead to increased uptake rates in sites. This will help ensure the CPSS pathway in each GP practice aligns with regional strategic priorities. To ensure that support is established, raising awareness of the CPSS at an ICB-level and aligning the CPSS with current ICB-level CVD priorities should be a focus. Selecting GP practices within ICBs that have a strategy that aligns with the CPSS (for example, mentions FH within their strategy report), should be considered for initial implementation as this may have a positive impact on buy-in.

Sites with less buy-in from GP practice staff completed fewer FH screenings. One GP survey respondent highlighted that the "*wider treatment room were not engaged*", so they were "*not successful on any level*". In this GP practice, four screenings were completed, resulting in an uptake rate of 12%. Interviewees noted the importance of a motivated driver to encourage screening. Motivated drivers at GP practices were typically those with a passion for CVD, or who had or knew someone with FH. If the key driver left the GP practice, the number of screenings was suggested to decrease.

Although ensuring GP practice staff buy-in is essential to increasing screening numbers, parent buy-in is also vital. One GP practice survey respondent noted that "*most parents declined*" the screening invitation, raising the importance of education on the benefits of early FH diagnosis. This GP practice had a low uptake of 2%, which emphasises the impact of parent buy-in on uptake. It should be noted that other factors, such as staff buy-in, may have also played a part in uptake.

The parent must feel able to ask questions to increase the likelihood of the parent agreeing to complete the FH screening. If the parent declines the screening, a potentially positive FH diagnosis is missed out upon. Missing screening when a child is one years old means they will likely not be screened for FH until into adulthood. This could lead to individuals unknowingly building up cholesterol in their body, which could result in an early death due to the increased risk of myocardial infarction and strokes that high cholesterol causes. Identifying such cases early allows patients to begin statin medication at the age of 10 years old and make lifestyle adjustments early, allowing these choices to integrate more seamlessly into their life, reducing the amount of cholesterol that builds up over time. This emphasises the importance of staff being confident in their knowledge of FH and ability to invite parents to the CPSS. Staff confidence is reliant on effective training. Overall, 72% of GP practice survey staff noted there was an appropriate amount of training provided to complete their role in the CPSS, indicating satisfaction with training content.

GP practice staff did not know to notify HIN staff that they had not received training or the Afinion POC device, delaying screenings. Interviewees noted that it was not always clear who the GP practice should contact for help. This hindered the success of the CPSS due to the delay in screening commencing. Ensuring HINs and GP practices are consistently communicating is essential for efficient set-up of the CPSS in GP practices. Communication was vital to allow HINs to support GP practices where needed.

GLHs had to change their existing pathway slightly, for example setting up the extraction method, however the pathway ran smoothly once the CPSS was implemented. Interviewees noted that GLH sites typically found implementation easier if they already had substantial resource. This suggests that GLHs typically experience some complications during initial implementation, however once integrated with existing pathways the CPSS becomes straightforward. The ease of implementation within GLHs likely contributed to the overall success of the CPSS due to the ability to complete genetic testing, however other factors such as the number of screenings completed appear more prominent in determining the success of the CPSS.

GLH interviewees preferred to include the VUS and PRS within screening reports. Reporting VUS ensures uncertain genetic variants in FH-related genes (for example, LDLR, APOB, and PCSK9) are tracked and reclassified as new evidence emerges, improving diagnostic accuracy. PRS helps identify individuals with high cholesterol due to multiple common genetic variants, ensuring those at risk receive appropriate care, even if no single FH mutation is identified. Tracking VUS allows for reclassification and earlier intervention for affected families, while PRS helps differentiate monogenic FH from polygenic hypercholesterolemia, guiding personalised treatment. Reporting VUS and PRS, alongside tracking updates in FH diagnostic criteria, would allow new cases of FH diagnoses to be identified, further contributing to the success of the CPSS. This highlights the importance of a feedback mechanism to ensure patients are aware of their change in FH diagnosis, allowing them to begin to make lifestyle changes.

One parent whose child had high cholesterol but not FH was interviewed on their experience of the CPSS. The parent understood the importance of FH screening but felt there was little guidance on next steps and cholesterol management in cases where no FH was identified. Patients with no FH diagnosis with high cholesterol levels would also likely benefit from the same lifestyle changes and guidance as those with an FH diagnosis. It is essential that such patients are also provided with the information they need to improve their health. Further, high cholesterol may be caused by FH that cannot be identified through DNA sequencing or another condition. In these cases, it is essential that patients receive further investigation around the causes of their high cholesterol to ensure that a suitable treatment plan is in place.

No parents of children with an FH diagnosis due to the CPSS were able to be interviewed. This means that the treatment plan following an FH diagnosis was not evaluated. Feedback on the next steps following diagnosis is essential to further understanding the success of the CPSS; if the treatment is not explained thoroughly or is not suitable, the patient may not make the necessary lifestyle changes or start medication when necessary. In turn, this would lead to a build-up of cholesterol, which could lead to myocardial infarction or a stroke.

Overall, screening uptake and FH diagnoses provides the metrics for success. The diagnoses rate in the pilot (0.11%) was slightly lower in comparison to Wald et al. (2016; 0.20%). The most optimal implementation strategies, revolved around communication and buy-in, where having whole site staff buy-in and ensuring communication across all sites is key to yielding high screening uptake.

4.2. Lessons learned from implementation [Q2]

Most interviewees suggested that the CPSS should continue, noting a range of reflections and recommendations to improve the service further. The main lesson learnt from implementation of the CPSS was the importance of buy-in from all involved in the CPSS. A lack of initial buy-in from decision-makers at the GP practice resulted in sites declining the screening invitation. Interviewees noted that, compared to GP practices with greater levels of buy-in, a lack of buy-in from staff at the GP practice resulted in fewer screenings completed. Of the surveyed staff who declined the CPSS invitation, 45% noted buy-in as a reason not to take part in the CPSS. One GP practice nurse survey respondent noted "*having a good team of admin and nurses working together to invite and implement is vital*." Therefore, all staff must buy-in to the CPSS before a GP practice decides whether to implement the service.

One reason GP practice staff may not buy-in to the CPSS was due to capacity concerns. GP practice staff face many challenges in primary care, such as rising demands, workforce shortages, and a lack of funding (British Medical Association, 2023), meaning their capacity is limited. Out of surveyed staff in GP practices who rejected the CPSS invitation, 91% reported staff capacity to have influenced their decision not to participate in the pilot. Staff must be selective over whether a new pathway should be implemented due to their capacity. That said, well-informed, trained, and engaged staff may be more likely to support the CPSS, as they can better understand resource requirements, gain confidence in the process, and work more efficiently.

Interviewees raised concerns around increasing immunisation appointment lengths and the perceived requirement to have more than one staff member to complete the heel prick test due to limited capacity. Not all HCP staff surveyed increased the length of the immunisation appointment (two out of seven staff surveyed did not extend their appointment lengths), suggesting that it is possible to complete the immunisation and FH screenings in 10 minutes. One interviewee noted they completed the heel prick test first to allow processing time in the Afinion POC device whilst the immunisations were completed to save time. Further, the implementation manual recommended two staff members should complete the heel prick test if the staff member is learning to complete the test (one to complete the heel prick test and one to hold the baby), however once they gain confidence, they could complete the heel prick test themselves. Explaining how the CPSS does not aim to create additional burden for staff capacity during staff training could result in a greater number of GP practices agreeing to complete the FH screening. Embedding such processes within training should foster improved confidence and efficiency levels within staff.

For staff to be motivated to complete screenings, they must first recognise the importance of FH screening. During GP practice training for the pilot, a patient from Wald et al. (2016) shared their experience with the screening service, providing a firsthand perspective on its impact. Additionally, a GP practice interviewee took the initiative to update their site's website with information about the CPSS, ensuring accessibility for both staff and patients. To further reinforce the CPSS's credibility, GP Federations, trusted sources among GP practice staff, released communications endorsing the service. These combined efforts helped staff recognise the benefits of implementing the CPSS, fostering greater engagement and commitment to its success.

Despite these efforts, one interviewee noted there was a perceived lack of evidence to support the need for the CPSS; Wald et al. (2016) identified 1 FH case per 250 patients screened, whereas the current pilot identified 1 FH case out of 1,000 screenings. Although this was the case, the diagnosis rates differed as Wald et al. (2016) identified FH through two additional pathways: children who had two high cholesterol readings, or children who had FH identified in their DNA sequence, but no high cholesterol. This raises the importance of communicating previous findings accurately to staff. Another interviewee raised concerns about whether nurses felt prepared to answer questions about FH, indicating a gap in understanding around the need for the CPSS.

While steps were taken to improve staff awareness, further improvements could enhance buy-in should the CPSS be implemented again. For example, clearly communicating that, despite lower diagnosis rates in the pilot, an estimated 220,000 people in the UK have FH, yet less than 8% are diagnosed (NHS England, n.d.-b). The CPSS is contributing to identifying these cases in line with the NHS *Long Term Plan* (n.d.). This reinforces the importance of widespread FH screening and addressing staff concerns about the value of the CPSS.

While staff generally valued the importance of FH screening and thought the CPSS should continue, some interviewees did not recognise the value the CPSS posed to the GP practice in terms of the incentives provided. Initially, GP practices were reimbursed £3 (or £5.50 if the GP practice already had their own Afinion POC device) for every screening completed, which later increased to £10 to increase the perceived value of the incentive. Despite this, one interviewee noted that GP practices did not always send invoices to receive payment for the screenings. Further, when surveying HCPs who declined the CPSS invite, 45% of staff noted reimbursement as a reason not to participate in the CPSS. This suggests that, despite adjustments, the financial incentive was not always viewed as a strong motivator.

Although being able to keep the Afinion POC device was intended to motivate GP practice staff to complete screenings, an interviewee raised concerns about the high cost of the cartridges the device required. Additionally, interviewees reported that some GP practices did not find alternative uses for the device valuable, with some staff asking to return the device. This indicates that the Afinion POC device alone was not a compelling reason for participation, reinforcing the need to consider ways to clearly communicate its benefits and encourage the device to be viewed as an incentive. Educating staff on the wider range of testing the Afinion POC device could achieve may help staff see the value of the device.

Engaging all relevant staff before implementing the CPSS is crucial for fostering buy-in. In the pilot, one interviewee recalled a GP practice staff member signed up to the CPSS without informing other staff members, leading to resistance. This was because staff felt unprepared and lacked the capacity to engage with the service effectively. One leadership role interviewee recalled that this happened in multiple GP practices. To prevent similar issues, all GP practice staff should have the opportunity to voice concerns, ask questions, and contribute to the decision-making process before committing to the CPSS. Further, ways to establish expectations for GP practices to complete screenings upon signing up for the CPSS should be explored, including ongoing measurement and holding GP practices accountable for the number of screenings completed.

Most staff reported satisfaction with the training received, evidenced through six out of seven HCP survey respondents feeling well equipped to implement the CPSS and 72% of GP practice survey staff agreeing that training was sufficient. Despite this, staff noted the need for more training on identifying patients, and ongoing management and support of patients. Further, the training video for the heel prick test was an animation; staff would have preferred a live video or an in-person demonstration to aid understanding. While the overall training experience indicated staff felt prepared, addressing these gaps could further enhance confidence and effectiveness in implementing the CPSS.

Clear communication between all stakeholders is essential for smooth implementation. Instances of miscommunication during the pilot had direct consequences on service delivery. One HIN interviewee recalled an occurrence where a GP practice did not communicate to the HIN that they did not receive their Afinion POC device or training. This delayed the implementation of the CPSS in this GP practice, leading to fewer FH screenings. Further, one GLH interviewee reported that the patient information on the screening samples was not always correctly filled in, and it was not always clear where to send test reports to. To improve communication, clear signposting of key contacts, processes, and expectations across the screening pathway is necessary.

While most GP practice staff surveyed (76%) found the Afinion POC device easy to use, technical issues occasionally disrupted the screening process. One interviewee reported that errors occurred in one out of every four tests, with another reporting errors occurred one out of six tests, requiring samples to be repeated. Despite this, some parents declined re-testing due to the discomfort of their child, reducing the overall number of screenings completed. In addition, a shortage of heel prick test kits created further challenges. One interviewee resorted to using finger prick tests after struggling to find where to purchase more kits, only to find they were sold out. Ensuring that staff have access to equipment and have sufficient training is crucial to maintaining screening uptake and improving FH detection rates.

Data from the pilot suggested disparities existed in screening uptake when examining ethnicity and deprivation. It should be noted that ethnicity and IMD breakdowns of individuals completing screenings in the CPSS pilot was unknown, so limitations should be considered when applying this finding. The results suggest that GP practices who were willing to participate were operating in less deprived communities with lower proportions of ethnic minority populations. Ensuring equitable access to screening remains essential, particularly in underserved communities. Lower uptake in more deprived areas suggests a need for targeted efforts to encourage participation. Without proactive intervention, those already facing healthcare disparities may continue to be underdiagnosed, exacerbating existing health inequalities. By standardising access to FH diagnosis and treatment, the CPSS can contribute to reducing health inequalities and improving health outcomes for all.

Nilsen et al. (2020) identified three characteristics of successful change in healthcare organisations: being able to influence the change, being prepared for the change, and valuing the change. The lessons learned from the current pilot align with these principles and highlight areas for improvement. To influence the change, GP practice staff must have opportunities to provide input before committing to the CPSS. Without this, there is a risk of disengagement and resistance,

as seen in cases where staff were not consulted before implementation. Being prepared for the change requires that all individuals involved understand the importance of FH screening and their roles in delivering the CPSS. This includes ensuring that training is tailored to specific responsibilities so that staff feel equipped to engage with the process effectively. Finally, for staff to value the change, they must not only recognise the significance of FH screening for patients but also perceive the incentives as beneficial to their GP practice. If staff do not see the value in participating, engagement will remain low. By addressing these factors, future implementation can drive greater staff buy-in and increase the number of FH screenings completed, ultimately improving early detection and treatment outcomes. Applying these principles will ensure that the CPSS is sustainable and impactful in the long term.

4.3. Contribution to the NHS *Long Term Plan* [Q3]

CVD remains a significant burden in the UK; there were approximately 1,000,000 hospital admissions for CVD in England in 2019/20 (The King's Fund, 2022) and CVD accounts for a quarter of all deaths in the UK (National Institute for Health and Care Excellence, 2024b). Early identification of FH is essential in reducing CVD-related morbidity and mortality. Therefore, assessing the CPSS's contribution not only highlights its impact, but also informs future strategies to mitigate CVD complications through early intervention.

Although Wald et al. (2016) yielded a greater diagnosis rate of 0.40%, identifying 40 children with FH out of 10,095 screened, this was achieved through identification of FH cases that either did not have high cholesterol or had two readings of high cholesterol but no genetic FH within DNA sequencing. In the current pilot, a second cholesterol test was not routinely performed unless the initial reading exceeded 5.9 mmol/L and no genetic FH was identified, in which case a follow-up test was conducted three months later. Cases with low cholesterol readings and a genetic FH diagnosis were not examined in the pilot, which may have contributed to the lower overall diagnosis rate (0.11%). When excluding such cases in Wald et al. (2016), this led to a diagnosis rate of 0.20%. As stated by Wald et al. (2016), having an FH mutation but not having high cholesterol levels is unlikely to lead to heightened risk of CVD. Therefore, identifying such individuals is not necessary as the FH mutation is unlikely to affect their health.

The NHS *Long Term Plan*'s (n.d.) ambition was to identify 25% of FH cases within five years. The CVD Prevention Audit (CVDPrevent; n.d.), provides two measures of FH: possible, probable, and confirmed FH and genetically confirmed FH. Within CVDPREVENT, the current prevalence rate of identified possible, probable, and confirmed FH is 0.22%[2] (125,633 according to 2022 figures; Office for National Statistics, 2023b). The National Institute for Health and Care Excellence (2024) estimates the actual England prevalence of FH is greater at 0.40% (228,424 according to 2022

[2] CVDPREVENT uses a range of SNOMED codes (NHS Digital, 2024a), hence is not directly comparable to the current pilot, however highlights an alternative measurement.

figures; Office for National Statistics, 2023b) using research from Akioyamen et al. (2017), which identified FH through high cholesterol either with or without DNA screening. Extrapolating findings from Akioyamen et al. (2017) may be a more accurate comparator to the current pilot as this identifies all individuals who could benefit from lifestyle changes (despite the pilot not examining those with high cholesterol and no genetic FH), rather than the estimated 220,000 total individuals with FH mentioned in the NHS *Long Term Plan* (n.d.) that includes individuals with genetic FH and without high cholesterol levels. This suggests that 228,424 individuals in England have FH and would benefit from an FH diagnosis if they do not already have one. If 7% are currently diagnosed (NHS, 2019), there are 212,434 people in England yet to be diagnosed with FH who would benefit from lifestyle changes or pharmacological interventions.

The CPSS identified two cases of FH. There are 212,434 people in England yet to be diagnosed with FH. This means that that the pilot identified 0.001% of the England population with previously unidentified FH. Extrapolating the CPSS diagnosis rate of 0.11% to the entire England population and assuming that everyone in England would be able to be identified through the CPSS, the pilot could have identified 62,817 people with genetic FH and high cholesterol levels. It has been noted earlier in the current report (Section 3.1) that the pilot was under-powered to replicate precisely the findings of Wald et al. (2016). Using diagnosis figures from Wald et al. (2016; those with either high cholesterol and genetic confirmation of FH or with two high cholesterol readings) gives a diagnosis of 0.28%. Extrapolation based on this rate would suggest that the CPSS could have identified up to 159,897 people if using a similar methodology (or 63% of the 253,947 people in England yet to be diagnosed with FH). This highlights the importance of completing a repeat cholesterol test within three months for all patients with high cholesterol levels; this could increase the diagnosis rates of the pilot.

The CPSS demonstrated potential in advancing the NHS *Long Term Plan*'s (n.d.) ambitions; the findings from the pilot were similar to Wald et al. (2016). By identifying FH cases early, the CPSS facilitates timely interventions, such as lifestyle advice and cholesterol-lowering medication, significantly lowering the risk of heart attacks and strokes. Moreover, early detection can extend benefits to family members, amplifying the reach and effectiveness of the screening efforts. These achievements underscore the CPSS's role in enhancing population health and reducing preventable CVD cases in England.

Despite this, there are opportunities for improvement to fully realise the CPSS's potential. Addressing the identified challenges, such as ensuring consistent buy-in across different regions and tailored approaches to individual GP practices, is vital. Strengthening the evidence base by addressing gaps and conducting further research can enhance the service's effectiveness. Ways of identifying cases of FH that cannot be identified through screening one-year-olds (for example, those without children), should also be considered. Additionally, fostering greater collaboration among healthcare providers and leveraging technology for better data management and patient tracking can streamline processes and improve outcomes. These enhancements are critical for ensuring the long-term success of the CPSS. Using these learnings to develop an approach that suits individual stakeholder needs is essential to reach the ambition set out in the NHS *Long Term Plan* (n.d.).

5. Recommendations

Suitable recommendations were collated based on previous literature and all data collected in the current evaluation, such as through staff surveys and interviews.

5.1. Preparing for implementation

Create a campaign to raise awareness of FH

A campaign could be created, in collaboration with HeartUK, to increase awareness of FH nationally through social media. This could be completed through social media posts for national awareness days, for example national cholesterol month in October. Flyers providing information on FH and the CPSS could also be placed in social infrastructures such as places of worship, nurseries, schools, and community pharmacies. Posters including information on FH and how to sign up for the CPSS should also be placed within GP practices. Awareness should further be made to health visitors and midwives to incorporate FH awareness early into routine discussions with parents. Increasing awareness of FH in all individuals is hoped to allow understanding of the importance of screening, providing parents and staff with motivation to engage with the CPSS.

Review the incentives provided

The financial incentive for GP practices of £10 per screening should be reviewed to ensure the financial incentive remains at the right level to support buy-in. Should future uptake grow as hoped, there would also need to be consideration of how or whether to provide a financial incentive to GLHs to ensure they are able to report in a timely manner. These recommendations will depend largely on the funding available, so are worthy of early consideration.

When mentioning the incentives as a reason to implement the CPSS into a GP practice, the incentives should be mentioned in a manner that ensures they are seen as desirable. The sunk cost effect refers to the increased likelihood of persisting with an endeavour after investing money, effort, or time (Kovács, 2024). Asking GP practices to pay a nominal fee may help ensure that the practice sees the device as more valuable due to the having psychologically *“bought-in”* to the screening service. Requiring a commitment up front may ensure that participating practices continue to drive screening rates, while those unwilling to commit may be discouraged from participating. This could lead to GP practice staff valuing the device more than if they were to receive this for free, facilitating uptake and buy-in.

Review the type of POC device used

Two GP practice staff interviewees mentioned that the Afinion POC device would yield errors. These rates, if not matching the error rates identified by the supplier, may have been exacerbated by lack of training or communication surrounding the device. Further, some staff did not consider other use cases for the device to be useful to the GP practice. Using a single supplier for the pilot

was useful as this standardised the training requirements and costs, simplifying this element. In future roll out, however, consideration of alternative POC devices such as those from different manufacturers could be explored to reduce the rate of errors and include alternative use cases that may be more desirable to GP practices. Further, using multiple POC devices within the CPSS may reduce the impact of shortages of equipment, such as the worldwide shortage of reagents that impacted some GP practices in the CPSS.

Although some interviewees recommended the use of buccal swabs rather than heel prick tests to make screening less invasive, Wald et al. (2016) highlighted the importance of identifying high cholesterol alongside an FH diagnosis. This is because a mutation can occur in the DNA, resulting in FH being diagnosed, however the patient may not develop high cholesterol. In the CPSS, it is important to identify only cases of FH that lead to high cholesterol to reduce the costs associated with the service and target screening only to those who may require lifestyle changes. Currently, the heel prick test is the most suitable way to test for cholesterol levels and FH. Should less invasive, cost-effective solutions become available, these may be beneficial to the service.

5.2. Inviting screening and testing partners

Implement the CPSS gradually

Begin implementation of the CPSS in a select number of GP practices and GLHs, before widening scale-up, to ensure smooth roll-out. First, GP practices that are likely to yield greater uptake levels should be focused upon. Such GP practices are those that have previously implemented CVD-related interventions (suggesting an established interest in a similar area) or have a high number of one-year-old patients compared to other GP practices. Once identified, the key contacts within each GP practice must be identified, alongside an individual who is best suited to contacting the GP practice (someone the GP practice knows).

This gradual implementation approach focuses first on GP practices and GLHs that have the greatest propensity for high uptake, increasing the likelihood of more FH cases to be identified, whilst allowing challenges to be identified and mitigated before wider scale-up. In turn, it is expected that challenges will be more easily overcome once mitigations are created. This involves frequent assessment of challenges and identification of the most suitable way to alleviate them. Therefore, GP practices must have regular, structured communication with HINs to raise awareness of the challenges and receive support to alleviate challenges.

Although implementing the CPSS in this way introduces the potential to negatively impact health inequalities at first, it is essential that roll-out is gradual to increase the chance of sustainably improved health inequalities across a larger number of sites. This would also ensure consistent assessment regarding whether the CPSS aligns with ICB-level strategic goals. If ICBs express commitment or are strategically aligned (for example, featuring FH within their strategy), then GP practices within the ICB should be initially focused upon. Following scale-up, the CPSS can be implemented in a greater number of GP practices, which would likely improve the effect of the service on health inequalities.

Tailor training to each staff type

The training available for future roll-out is dependent on the funding available to the CPSS. The most impactful method of training would involve hosting training sessions in person at each GP practice and include a session from sites who have already successfully implemented CPSS in the past. If this is not feasible due to funding constraints, training could be held online. Training should be mandatory for as many staff as possible at the GP practice and booked in advance to allow staff time to complete training before implementation begins. Clear expectations of each staff member's requirements, role, and responsibilities should be defined during training.

Creating training materials specific to each staff member's role in the CPSS would facilitate understanding. For example, nurses should receive training on how to complete the heel prick test and use the POC device. The heel prick test training would optimally consist of a live video (rather than an animation) to demonstrate the heel prick test accurately. The video would emphasise the need for only one staff member to complete the screenings once they are comfortable to do so, alleviating capacity concerns. Other staff, such as receptionists, should receive training on what FH is, and how to invite parents to complete the FH screening for their child. This ensures that all GP practice staff members know what the CPSS is, its intentions, and its importance.

Ways to establish expectations for GP practices to complete screenings upon signing up for the CPSS should be explored, including ongoing measurement and holding GP practices accountable for the number of screenings completed. The implementation manual should also set out roles and responsibilities for each staff member at the GP practice and each stakeholder organisation. Finally, an initial Q&A session should also be held for staff members of the GP practice to address any concerns and encourage buy-in. These steps are expected to encourage awareness of FH across all staff groups within the GP practice, intending to increase buy-in.

5.3. Screening process

Ensure accurate data collection

The data collection template must be standardised across all GP practice data entries. Further, data entries must flow into the main data collection template using formulas to show where the values came from. This allows for greater understanding of the figures, reducing the likelihood of human error.

In the data screening template, the number of patients invited to the screening was also included. The number of patients invited should only be recorded if the figure can be routinely collected and trusted or verified. A potential method to ensure accuracy is to create a SNOMED code for FH screening invitations. Placing this on each record where an invitation was sent would enable aggregation and verification where needed.

When tests are sent to GLHs, a more digitised approach should be taken. Here, patient data should be linked to the sample before sending for testing. This allows GLH staff to know with certainty which patient the test is linked to, allowing the report to be sent back to the correct GP

practice and patient record. This could simplify or automate monthly reporting, increasing the efficiency and accuracy of the reporting process.

The proportion of tests sent to each GLH from each GP practice should be measured and examined; previously, this data was not available. This would allow further insight regarding whether specific areas may have higher FH prevalence compared to other areas. Differences in FH diagnosis rates in each area of England could be due to the genetic makeup of the population, the number of one-year-olds eligible for screening, or the number of screenings completed.

A feedback mechanism should be in place to report the VUS and PRS scores in GLH test reports for FH screening. This would allow the patient to be aware of the information, should this be relevant to their future care, ensuring transparency when required.

Signpost contacts and enhance the level of support provided

Finding ways to adapt the manual to simultaneously suit the needs of several GP practices will satisfy a greater number of staff members. Some staff preferred the manual to be short, whilst others preferred the manual to be longer. Making the manual adaptable, such as by creating an interactive chatbot, could help answer questions in as much detail as the staff member requires, satisfying a range of preferences.

Within the implementation manual, key contacts for all points of the pathway should be established for all stakeholder organisations. Further, ensuring regular contact between HIN and GP practice staff to allow catchups with progress will also improve communication across the service. This can allow GP practices to raise issues when they arise, where HINs can provide support to alleviate these challenges.

A community of practice can also be set up to provide further support, allowing GP practices to troubleshoot. This should be tailored to specific regions, rather than a national approach as previously used. Providing a space for support fills in any gaps in the implementation manual that may be unique to a specific GP practice, allowing challenges to be mitigated as they arise.

Patient information templates in nine different languages are already available, however not all staff were aware of the templates. Increasing awareness of templates is anticipated to enhance accessibility and patient understanding of FH, ensuring parents understand why they are signing up for FH screening and the importance of screening for FH.

Consider diagnosing FH through repeat cholesterol levels for patients with no FH mutation in DNA sequencing

Although the current pilot was able to identify cases of FH through DNA sequencing, FH can still be diagnosed through two cholesterol measurements within three months that yield high cholesterol levels. The current pilot did complete follow-up total cholesterol tests for children with no FH mutation identified through DNA sequencing, however, did not diagnose these patients with FH. This means that potential FH cases may have been missed, however patients were still provided with guidance on lifestyle changes. Any future CPSS implementation is suggested to

collect follow-up data on children with initial high cholesterol readings, but no FH mutation identified to determine whether they can be diagnosed with FH.

Ensure individuals with no relation to one-year-olds are screened for FH

Individuals who are not related to eligible one-year-olds cannot be identified through the CPSS. Therefore, screening programmes that can identify and screen such individuals should also be implemented alongside the CPSS. An example of this is the lipids and FH programme, which identified patients through searches of primary care patient lists such as EMIS and SystmOne and ensured that NICE treatment guidelines were followed. This would further drive identification of as many individuals with undiagnosed FH as possible, contributing further to the NHS *Long Term Plan*'s (n.d.) ambition.

5.4. Ongoing measurement

Gain regular feedback from staff and patients

Regular feedback should be gathered from staff and patients, for example through surveys, to identify any issues occurring in the pathway as they arise. Ways to mitigate issues should be identified and fed back to individuals. Continuous improvement of the CPSS will help increase the number of screenings and facilitate seamless integration with existing pathways.

Gain feedback from individuals with an FH diagnosis due to the CPSS

Feedback from parents whose child had an FH diagnosis was unable to be gathered as no parents volunteered for interviews. It is important to understand whether parents received enough information regarding the FH diagnosis and whether they received enough support to manage their child's (or their own) FH effectively.

6. Conclusion

The CPSS yielded similar findings to Wald et al. (2016). Variations in uptake indicate that some GP practices could enhance their performance further. Qualitative analysis pin-pointed buy-in and communication as key drivers for success; higher buy-in and communication led to more screenings. To maximise impact, future roll-out should prioritise ways to strengthen these factors, helping to identify 25% of undiagnosed FH cases as outlined in the NHS *Long Term Plan* (n.d.). In turn, more individuals with FH can be diagnosed early, enabling them to make crucial lifestyle changes before it is too late. This underscores the CPSS's role in enhancing population health and reducing preventable CVD cases in England.

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8. Appendices

8.1. Appendix A: Cholesterol readings

Cholesterol data was provided by Health Innovation NENC. This was analysed through descriptive statistics. There were 928 cholesterol readings provided between November 2021 and October 2024. Total cholesterol was calculated where possible, resulting in 881 total cholesterol readings. The median total cholesterol level was 3.7 mmol/l (minimum = 2.0; maximum = 7.5).

8.2. Appendix B: Interviewee suggestions to improve the service [Q2b]

Future of the CPSS

GP practice

GP staff interviewees noted that the CPSS should continue and that they would support this, however this required financial incentives and an assessment of the time requirements of staff. Overall, five out of seven HCPs surveyed (71%) would recommend participating in the parent child screening service to their colleagues, whilst two would not. Of those who would recommend, HCPs noted this was due to its ease (*n* = 3) or the importance of diagnosis (*n* = 2). Those who would not recommend the CPSS to colleagues noted this was due to the time-consuming nature of the service (*n* = 2), where one HCP noted "*there is not enough allocated time to contact patients and send out letters in addition awaiting a response from parents prior to the clinic date. The clinic requires 2 nurses and and [sic] extended appointment, neither of which in the current climate is achievable [sic]*". One HCP also noted that the service was "*fiddly*".

HIN

HIN staff interviewees showed variation regarding whether they thought the CPSS should continue. On one hand, interviewees suggested the CPSS should continue due to the importance of testing; the NHS are not currently reaching their intended FH targets and there are patients who are unaware of their risk. The earlier patients can be identified, the better, even if the uptake numbers are small. One interviewee suggested the use of the buccal swab (collecting DNA from the cells inside a person's cheek with a swab). This would mean children could complete the test at home painlessly. Despite this, another interviewee suggested that the buccal swab would be unsuitable as they suggested there was variation in the quality of the DNA sample collected using this method.

Some HIN staff interviewees suggested the CPSS should not continue as the chance of identifying someone with FH was rewarding, however the diagnostic figures were disappointing. One interviewee questioned whether the correct individuals were being tested and whether a difference is being made due to the CPSS. Alternatively, one interviewee suggested the test should be part of general diagnostic referral and should come in the same pathway as generic cases. This would allow the PRS score to be provided too. This suggests that staff are questioning whether their work has made an impact in diagnosing FH cases in line with the NHS *Long Term Plan* (n.d.) and whether examining other cohorts could yield greater rates of diagnosis.

HIN interviewees also highlighted that whether the CPSS were to continue is dependent upon the funding available. They suggested that the CPSS would be less likely to continue without the incentives and support available. Further, some practices also wanted to return the Afinion POC device, suggesting they no longer would continue screening without funding or use the device for other pathways.

VCSE

The VCSE interviewee suggested that the learnings from the CPSS pilot must be reviewed, and recommendations must be made to improve the service. They wanted to understand what the incentive should be for GP practices and how GP practices may want to be involved in the CPSS.

GLH

Three out of the six GLH interviewees suggested the CPSS should continue, with one suggesting the CPSS should not continue as it currently is. GLH interviewees highlighted the importance of screening for patient awareness of their FH and to reach targets set by NHS England. The interviewee who suggested the CPSS should not continue as it currently is noted the need to investigate what is happening with children with otherwise healthy lifestyles but high cholesterol as the CPSS was too "*light touch*". Another GLH interviewee wondered whether the correct individuals were being screened due to the lack of positive FH cases identified. They felt it was difficult to know whether they were making a difference through the FH screening.

GENInCode

The interviewee from GENInCode suggested that GLHs should use GENInCode to ease the burden of FH testing and help reduce turnaround times; GENInCode was suggested to complete tests in 10 to 15 days, whereas the NHS was suggested to complete the tests in three to six months. This could free up vital resources for testing required in a shorter space of time, for example, faster rapid cancer screening tests. Despite this, the interviewee raised that when determining the budget used, the NHS does not allocate a specific budget for this, meaning it may be difficult to isolate a sum of money that could be allocated to analysing data and sending out final reports. The GENInCode interviewee also suggested the use of the SITAB Portal to control and store sample data and reports for up to 30 years. They noted that this could help the NHS as all clinicians would be working from the same database rather than multiple different databases.

Suggestions to improve the CPSS

Include the PRS and VUS in reports

GLH interviewees suggested inclusion of PRS scores as they found these in approximately 50% of referrals. One interviewee questioned whether examining only five genes for FH was enough and whether enough cases were being picked up due to this, although it should be noted that this is part of standard practice, and not specific to the CPSS. Further, interviewees also suggested including VUS, where parents could be recommended a referral to a lipid clinic for family testing. It was noted that the VUS results should be explained to the patient by an FH specialist nurse to ensure the results are communicated correctly.

Increase screening numbers and GP practice uptake

GLH interviewees expressed the need to increase screening numbers to identify 25% of the FH population outlined in the NHS *Long Term Plan* (n.d.). The staff member noted that uptake depended on how patients were communicated with to encourage them to complete the screening.

A GP practice interviewee suggested that including screening information in churches and community pharmacies may help with uptake. One interviewee also suggested broadening the eligibility criteria for the screening. One HIN interviewee noted the need for GP practices to approach parents in an upbeat manner as this was noted to impact parent uptake. They noted that GP practices which were more proactive and motivated were more likely to have higher uptake. Another HIN interviewee suggested a campaign to raise awareness of FH as they felt this was widely misunderstood and was viewed as a specialised area. This would help raise awareness across parents, GPs, and nurses to help encourage confidence in staff inviting parents to the screening and understanding in parents deciding whether to complete the screening.

Create a community of practice

To improve the CPSS, HIN interviewees suggested a community of practice would be beneficial. They suggested to create this early on to help with GP practice buy-in and troubleshooting. One HIN interviewee noted that a local clinician who has expertise in FH could provide support to nearby GP practices in the form of presentations and Q&A sessions.

More promotion at a strategic level

Two HIN interviewees suggested encouraging uptake at a strategic level. For example, encouraging uptake at a PCN or ICB level instead of a GP practice level could help gain interest; if the PCN is onboard, the GP practice may be more enthusiastic about getting onboard. Another HIN interviewee suggested advocacy from organisations that provide key guidance such as the British Medical Association, Royal College of General Practitioners, and Local Medical Committees. Here, they suggested that GP practices would be more likely to listen to such organisations if they advocate the CPSS.

Enhanced communication across organisations and stakeholders

One HIN interviewee suggested the need to take a proactive approach, rather than the current hands-off approach. They felt they could have provided GP practices with more support after giving them training and the Afinion POC device. Further, another HIN interviewee highlighted that they would have liked to have known monthly who received the Afinion POC device and training. The interviewee recalled that the equipment was sent to a different site, and they were not aware of this. The interviewee suggested creating an online system to allow tracking of resources.

Digitisation

GLH interviewees suggested the need to allow reports to be sent digitally, rather than via post to help with larger scale uptake. It was often not clear where the GLH staff should send the reports to; ensuring there is a named contact for each GP practice would generate procedural efficiencies. Further, GLH interviewees also suggested the need to use online forms; handwritten forms were often difficult to read.

Improve data collection

GLH staff interviewees suggested the need for the monitoring forms to be updated when results are received, tested, and analysed. In the current process, staff are required to file this information once a month, however this yielded issues where multiple cases were recorded in error. Further, the patient's postcode was used as a way to identify a patient, however this can become confusing when multiple patients have the same postcode (for example, if twins were screened). Here, staff suggested the need for use of a different patient identifier to improve the quality of the data collected.

Ensure staff awareness of the CPSS

The most successful implementations occurred when doctors, nurses, and administrative staff all bought in and fully understood the processes. One example of unsuccessful implementation involved a GP who was enthusiastic to start the CPSS, so signed up and organised the resources to arrive, however nurses were not aware of the CPSS. The nurses did not have capacity available to complete the screenings and did not know how to complete the heel prick test. Further, receptionists were unaware of the CPSS and what this entailed, so were unable to explain this to parents. This expresses the importance of ensuring that staff are aware of the CPSS before the GP practice begins to implement the programme.

Review the incentives provided

A leadership role interviewee noted that the £10 incentive was better than the £3 incentive. Despite this, the VCSE interviewee questioned whether £10 was enough as an incentive and suggested that this should be compared to similar pathways. It was also noted by a leadership role interviewee that not all GP practices sent an invoice to receive the payment for completing screenings. When invoices were received, they were sometimes sent months later than the screenings were completed instead of after one month as expected. One leadership role interviewee suggested that there may be difficulty with future funding for the CPSS, however, due to the perceived lack of engagement.

GLHs are commissioned on a block contract, meaning they are paid a set fee regardless of the number of samples they complete. Interviewees noted that the total tests undertaken for the CPSS was much lower compared to other pathways. A GLH interviewee noted that they would need to understand the number of samples they expected to be analysed before they agreed any payment.

One leadership role interviewee suggested taking the Afinion POC device away if the GP practice did not complete any screenings. Another leadership role interviewee suggested looking at other alternatives that could be used, which may be more accurate or provide more of an incentive. One GP practice staff member suggested that they were unlikely to use the Afinion POC device as the cassettes were expensive, costing approximately £6 to £7, which could not be funded internally. Therefore, it was suggested that the Afinion POC device was not seen as a reason to engage in the CPSS. Finding other sources of incentive may make the CPSS more attractive to GP practices.

Host in-person, GP practice-specific training

In the previous CPSS study, in-person training was provided, which lasted for half a day. For the CPSS pilot, training was offered as a 45-minute online session. One HIN interviewee noted this was too short and felt that nurses could get distracted during the training, impacting their understanding. In-person training specific to each GP practice was suggested by HIN interviewees to improve nurse understanding of the CPSS and how to complete screenings. Further, GP practice survey respondents recommended education to all GP practice staff, where "*having a good team of admin and nurses working together to invite and implement is vital*".

Explore other methods

Interviewees and GP practice survey respondents suggested changes to the CPSS, such as:

- Using methods other than the heel prick test, such as buccal swabs, which are less painful
- Considering conducting screening outside of the one-year immunisation appointments
- Considering conducting screening in other age groups, such as younger adults
- Considering conducting screening in other sites, such as community diagnostic centres (CDCs)
- Allowing GP practices to have a screening clinic, rather than screening being completed during the immunisation appointment
- Including the CPSS as a national screening service and part of routine GLH sampling
- Including patient leaflets, posters, and invitation letters in different languages and ensuring that these are available at the start of implementation

Improve the quality of parent information provided

The parent who was interviewed noted that they would have liked more information online surrounding FH, why the screenings are completed, and what concerns parents should have. This information was suggested to be included in the material available for health checkups online. They would also have liked more guidance on next steps if they do not have FH but do have high cholesterol.

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