Diabetic Eye Screening

Discovery Work

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Diabetic Eye Screening Wales

Why was Discovery needed

Demand far exceeds capacity
- Currently 184,500 participants registered
- Currently 88,500 are due or overdue eye screening
- Longest waiting participants have been waiting 31 months

Limiting factors
- Currently screening out of 60 venues (was 140 pre covid)
- Having to fund private venues: scouts hall, community centre and football ground – no recurrent funding
- Staffing: sickness, turnover, culture, complaints

Recovery of the Programme is unlikely with current service model
Need to have a Transformation Programme starting with Discovery

Understanding our users
The research in numbers

- **28** 1-2-1 interviews held with service stakeholders
- **30** interviews with participants at screening clinics
- **6** epics and **47** user stories identified in research, during **92** interviews
- **185** survey responses, including 5 in Welsh
- **55** RRS survey responses
- **66** responses to the internal user survey
- **26** 1-2-1 calls with consenting participants
- **2** patient reference groups
- **5** participants who do not attend
- **3** participants of the Retinal Review Scheme
- **3** clinics visited
- **3** interviews with other nations
- **18** interviews with members of the screening team
- **1** interview with a mobile service user
- **6** interviews with users who have access needs
- **1** interview with representation of Hospital Eye Services
- **2** participants of England screening services

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Research: Speaking, and learning from our users

+200 people

Mapping: Understanding the research

Personas: defining manageable user groups

5 personas

Task flows and User stories: detailing key areas to focus on

31 tasks

As a service user, I want to book myself in for an appointment, but when I try to, I can't ahead of time.

As a service provider, I need more training and support so that we as a team can strive for continuous improvement

47 stories

Understanding users and their needs - The persona methodology

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"Managing diabetes is much a mental illness as a physical one"

The Burdened

"Diabetes is part of my life, I know I have to deal with it, and I don't let it get me down"
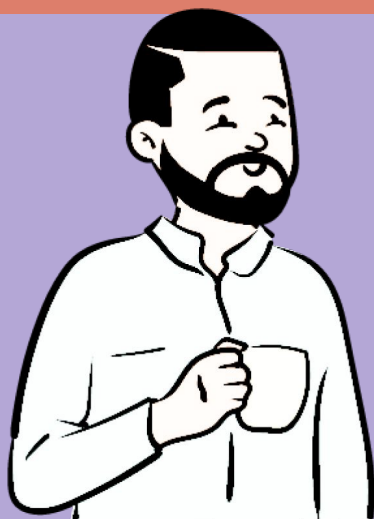
The Diligent

"I'm trying to keep up with the appointments, but it's tough"

The Caregiver

"I do whatever needs to be done to make the service work"

The Conscientious, service role

"I could be happier in my job"

The Guardian, service role

Understanding users and their needs

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Bex, feeling burdened

Bex works full time in a job that has recently moved to hybrid working. She was diagnosed with Type 2 diabetes five years ago. Bex struggles with the adjustments she needs to make to her lifestyle in order to live well with diabetes; the repercussions feel too far off to matter, and too intangible and frightening to grasp. **Consequently, her motivation to deal with diabetes is fairly low, with sporadic attention.**

"My diabetes is a daily burden"

"Managing diabetes is much a mental illness as a physical one"

"Learning more about my diabetes would make a tremendous difference"

"Check-ups are an inconvenience; I ignore them until something goes wrong"

Trying to manage my work-life-health balance

Joining my online support group

Frantically getting ready for an appointment

Looking for my health documents

8 Confident
GDS DIGITAL INCLUSION SCALE

Needs

- Appointments that are flexible, and don't clash with my 9-5 job
- To better understand the results, implications and actions from her tests
- To practice good self management
- To see their health data trends over time
- Engaged staff that can support me*

Challenges

- Confident about technology; finds paperwork and letters difficult to manage
- Being overwhelmed by all the tasks to manage diabetes that need to be performed daily*
- To take a more proactive role in their diabetes care*
- Understanding the reasons why care and attention to their health is important*

*Inferred insights that has not yet been validated with sufficient user research

Understanding users and their needs - Burdened

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Flexible appointments that fit in with my 9-5 job.	I receive a letter with a date, time and venue for my next appointment.	I speak to my boss to arrange to get time off but it isn't convenient.	I call the number to a arrange a time when I can get time off or before or after work.	No suitable appointment before or after work or day when my boss was happy for me to take time off.	I don't attend.
Future task:	I receive a letter with a date, time and venue for my next appointment. There's a paragraph about why it's so important to my health to attend.	I go online to change my appointment. I see options for an evening appointment.	There's an opt-in to receive an SMS notification reminder, or a phone call reminder just before, so I don't forget about it	The day before, I answer a call to check I have everything I need for my appointment or any questions I might have. I attend my appointment - it wasn't so bad!	Perhaps I will go again next year? There's an opt-in to receive an SMS notification for next year, and an option to select my preferred screening location and/or preference for evening appointments.

I need support to understand result from the screenings & implications for my care.	I attended my screening appointment although I didn't fully understand why it was important.	I received my results letter but I didn't understand the implications and what I needed to do next.	I called the screening service but it was difficult to get through but eventually spoke to someone.	My image showed that I have some disease in one eye but I am still not clear what I need to do about that.	I am feeling very worried.
Future task:	I attended my screening appointment having read the accompanying booklet and watched some youtube videos that showed people like me.	I received my results letter which explained the findings and what that meant for me.	I was able to web-chat with someone who explained my results to me.	I know I have some retinopathy in one eye and that I need to pay more attention to managing my own diabetic care.	I have made an appointment with my GP/diabetologist to plan the changes I need to make to my self care.

I know I need to manage my diabetes better but that is really hard.	I have got an appointment for my annual diabetes check.	I have been trying to find my recent results but I am not good with looking after documents and usually the practice nurse doesn't have the information.	My practice nurse wasn't aware of my screening result and she also thought I was overdue in receiving an invite.	The practice nurse said that she would ask my GP to write to DESW to tell them I was overdue an apt	I am trying to make the recommended health changes, but I'm worried that I might not being doing the right thing; and that maybe my appointment is overdue.
Future task:	I have got an appointment for my annual diabetes check.	I have logged on to my NHS Wales app and checked that all of my recent test results are there.	I went through the test results with the practice nurse who explained changes I could make to manage my diabetes. she told me I was overdue an apt for eye screening.	Starting with the diabetic eye screening website I found some helpful online resources that have helped me to manage my condition.	I was also able to book an apt online. I have changed my diet and now feel more confident in managing my care. I feel supported to do this.

I've been taking care of myself and feel I'm well enough to try for a baby.	I wonder how being pregnant will affect my diabetes control.	I look online for more information. There are so many suggestions and conflicting opinions, I leave more confused as ever.	I don't want to wait for my appointment to ask, so I call the service to see if I can get any support on this question.	The call is helpful, but I can tell the person I spoke to is very busy and was kindly trying to get me off the call as soon as possible.	I got the gist of things (i can get pregnant!) but I'm also quite unclear of the consequences.
Future task:	I wonder how being pregnant will affect my diabetes control.	I go online to the 'Diabetic Learning' where there is lots of verified information, and I can find a topic that's relevant.	I don't want to wait for my appointment to ask, so I go online to the WhatsApp chatbot and verify my answers.	I feel satisfied with the answers I was provided with. I confirm my interpretation my with friends.	I learnt that I am able to get pregnant right away, all I need to do is notify the service, and go to my appointment.

Understanding users and their needs - User journey task flows

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I have questions I need to ask about the service and my health from the staff	I'm feeling overwhelmed by all the tasks and activities I need to do to manage my diabetes, and also my work & life.	I'm not sure who I can ask, my friends and family don't know.	I call the service to ask some of the questions, but I don't feel comfortable asking personal questions in this way.	I wait for my GP appointment / my screening appointment to ask more questions.	After my appointment, I still have ongoing questions, and I'd like to meet others like me.
Future task:	I'm feeling overwhelmed by all the tasks and activities I need to do to manage my diabetes, and also my work & life.	When my first appointment / results letters arrive they have a booklet that explains the service and the results in more detail.	When I go to the booking appointments portal there is a FAQ section with helpful links on the Internet.	At my appointment, I am shown the pictures from the last screening, and the changes in my health are explained to me.	There is an online/in-person support group that I can join, so that I can meet others like me.
The letter arrives and reading it makes me feel anxious and confused	My results letter arrives and reading it makes me feel anxious and confused, because there are medical terms I don't understand, and the tone is 'cold'.	I'm overwhelmed with anxiety, so I put the letter away for another day.	Time passes until my next appointment.	I don't look at the letter again until I need to go to my next appointment. I bring it with me.	At the appointment, the terms and results are explained to me; and I feel much better. I know what I need to do.
Future task:	My results letter arrives and reading it makes me feel anxious, but the tone is 'helpful' and the information is explained.	In the letter there are medical terms, that have explanations and visual diagrams. There is also contact information if I have questions.	I contact the team by telephone/email/webchat and ask them some questions I have to explain and understand my results better.	I feel confident that I know what I need to be done next.	

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Core recommendations

Engage with partners and governance on designing a mixed service model, to include optometry, to meet the needs of the participants and to reduce load on screening services and Hospital Eye Services.

Adopt a mixed venue model based on needs including location, accessibility, more flexible clinic hours, transport options where available.

In parallel with the strategic activities progress a prioritised set of incremental improvements that will have an impact in reducing workload and the frustration of staff and improving the experience of participants.

These small incremental improvements will build into significant change.

Continue to build awareness of tactics to test ideas at small scale, learn and move on iteratively.

Instigate a programme of upskilling in digital and data across all roles identifying skill gaps so that the team is able to take more active responsibility for the tools that they use including building a more collaborative relationship with the supplier.

Conduct a holistic persona-based content review to ensure information being shared is relevant & available in required formats.

Instigate a series of staff engagements to promote a culture of continuous improvement including exploring ways of making teams more connected and effective; routinely engage staff in reviewing feedback and developing ideas for improvement; and celebrating success.

Understanding user needs

Internal needs - system users

The system

- The current journey is manual, paper based and perceived as onerous. Opportunities have been identified to address pain points and help define a more simplified journey.
- A lack of understanding how to use current technology is resulting in an increase in paper based processes. This risk needs mitigating in conjunction with upcoming system upgrades.
- Define both the service metrics and what good looks like and continue to communicate this to the operational teams.

Capability

- **The service relies on systems and data to be effective. The DESW team need equipping to manage a digital and data service.**
- **Review procedures to make them more accessible and usable.**
- **Utilise and train teams on technology capabilities to reduce manual overheads.**
- **Explore the introduction of mixed roles for increased flexibility and career progression.**

Operations

- Celebrate success in participant experience and implementing small improvements.
- Explore ways of making teams more connected and effective through improved communication and availability of information.
- Discover the communication needs of the teams, carry out more frequently, invite feedback & act on it.
- Routinely engage staff in reviewing feedback and developing ideas for improvement.
- While adequate more appropriate equipment should be considered, based on user need if a mixed service model is to be implemented.

Solve a whole problem for the users

Understanding user needs
External needs - service users

Convenience

- Venues need to be both convenient and accessible with more mobile or bespoke offerings available as needed.
- A clinic schedule that accommodates all participants.
- Implement appropriate screening intervals, for both low and high risk participants.
- Discover what is realistic in relation to combining diabetes health checks during screening.

Information

- **Do not allow the outsourcing of letters to constrain improving content.**
- **Do carry out a content review and redesign with targeted content for those with specific needs.**
- **Engage with other partners on both the Diabetic pathway and other screening services to improve information flow.**
- **Collectively continue to understand participants needs and improve the end to end service. This includes those such as those in longer term care.**

Engagement

- Focus alpha testing approaches to engaging with the following groups to improve the perception of the service:
  - Non attendance
  - Young adults
  - Those with protected characteristics
  - Those at first diagnosis
- Engage with GPs and practice nurses to understand the benefit of a joined up approach to engaging with these groups.
- Use tools such as Civica and CFES for gathering and responding to feedback planned in the alpha phase.

Solve a whole problem for the users

Provide a joined up experience across all channels

Channels

Simplify start journeys for both system and service users with a shift toward online booking, use of preferred locations, ongoing research into how all users can better utilise both the back end system and any online services and continual testing of revised any task flows.

Simplified journeys

Continue to develop task flows with policy and operational teams to gain input into ongoing improvements, test the use of open bookings with participants through both online and offline channels, work with content designers to refine and lest letters and other correspondence. Carry out further research on improved referral processes.

Feedback loops

Work with the engagement team to map out stakeholders and their needs with a view to testing a series of incremental improvements that will benefit those involved in the diabetic pathway. Establish user groups, seeking feedback and testing improvements as the service develops.

Assisted digital

Baseline current use of channels across the pathway, establish opportunities to shift usage to more efficient routes and inline with task flows look to nudge internal and external users to adopt more efficient ways of working. Ensure current routes that support users with literacy or physical disabilities and those who prefer not to use the internet are efficient and effective.

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Make the service simple to use

Multi venue

Adopt a mixed venue model based on needs including location, accessibility, more flexible clinic hours, transport options where available.
Enable Online booking for those who wish to use this channel, start a shift to more open booking for those cohorts who are harder to reach.

Content

Utilise the skills of content designers to carry out a review of all content including, letters, results, websites, correspondence and education material to update and test with participants information that meets their needs and increases uptake.
Do this for all internal forms and information exchanges across the pathway.

Roadmaps

Working with policy and operational teams look to develop a longer term roadmap of options and opportunities, looking to build on good practice across that pathway, within other screening services and that across Public Health Wales.
Develop longer term view on technology and data improvements.

Usability testing

Set up working groups both across system and service users establishing a regular drum beat of usability testing supporting the ongoing development and iteration of task flows, options and opportunities.

Make sure everyone can use the service

Equity

Continue research into those groups who are disadvantaged or who are prevented from using the service though physical, mental or social environmental factors. Identify approaches to maintain continued engagement with these groups to understand their needs and provide a bespoke service where needed.

Digital Inclusion

Understand the digital maturity of the system and service users and ensure the service is designed to meet these needs.
Continue to develop the service to meet the needs of those that are willingly unable, reluctantly online or learning the ropes.
Ensure services are tested against required standards.

Excluded groups

Ensure both the online and offline service is designed to accommodate all users with access needs. Engage with user groups to ensure the needs of the service model are understood, and opportunities identified, ensure equipment meets the needs of the service, ensure content is targeted and compliant.

Continual testing

Maintain an ongoing cycle of identifying needs, opportunities and potential solutions for testing with internal and external user groups. Ensure there is an understanding of desired outcomes, how improvements could benefit the service and how to measure success.

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Using the right technology

Choose the right tools

Online booking capability will reduce the current manual over-head of the service on the operational teams. As part of a mixed model the use of OptoMize by Local optometrist should be considered as should the use of additional communication tools. There are a number of OptoMize modules including Webview, auto scheduling and capacity management that meet user needs that should be considered in the short term as more strategic roadmaps including capability such as AI are established.

Use of Data

Data is generating a large number of pain points across both internal and external user task flows. While work is underway on cleansing data by the admin teams an ongoing and systematic approach is needed to understanding options and opportunities that will address known issues with participant data, quality of images, information sharing across the pathway and performance reporting.

Integration

Roadmaps should consider a series of integrations across both primary and secondary care with systems such as the Welsh GP record, GP Connect (GP2DRS) and more strategically the Clinical Data Platform.

In addition to this short term focus should be on loading results into the Welsh Clinical portal and receiving data from the Welsh Patient Administration system.

Operate a reliable service

Digital and Data capability across the team is limited generating pain points and increasing inefficiencies. Understanding the capabilities needed, across supplier management, training, performance analysis and system configurability is crucial to alleviate current pain points while ensuring efficiencies are eradicated as investment is made in more modern systems.

Using the right technology
Equipment

Choosing the right tools

Inline with recommending a mixed service model, a mixed approach to equipment is also needed.

Understanding the wider needs in relation to equipment is key to delivering a more efficient and equitable service. Those with cataracts for example are currently excluded from clinics.

It is clear to team have a good grasp on available equipment and how this can benefit the service. The key here is to tie these to user needs that not only address pain points for staff and participants in clinics but deliver a flexible more mobile service for those that either cannot of those who chose not to come to clinic.

A mixed service, through mobile clinics, use of community optometrists, DESW venues, those provided by LHB and bespoke services for those in long term care, those housebound or those in prison provides and opportunity to provide an equally equitable set of equipment.

Current image quality is seen as a possible cause for excessive referrals therefore a separate internal discovery should be carried out, in conjunction with the review of HES referrals to understand the needs of those involved and impacted by the quality of grading to determine appropriate options and opportunities to address this including the ability to more efficiently share data across the pathway. This discovery should validate the assumption that the funding model, as with ability to source venues, is impacting the use of more appropriate equipment.

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Research in alpha
What next

Assumptions to test

- Alternative approaches for engaging with those who regularly do not attend will improve uptake.
- Online booking reduces burden on the admin teams.
- Targeted letters will increase participation.
- A revised funding approach will increase capacity..
- A simplified journey for system users will improve confidence in the service.
- Improving digital and data capability will reduce manual overhead and enable the service to be more responsive

Questions to ask

- Evidencing needs through continued research into the expectations and service needs for different user groups,
- What support might users need?
- How does the service support digital uptake?
- Impacts of data quality pain point- simple ways for all types of users to correct data e.g. Change of address and mobile numbers.

Establish User Groups

- External/Internal personas through ongoing regular research and user testing;
- Those that do to regularly attend screening appointments;
- Those groups engaged with the RRS;
- Young adults and those who are attending their first screening appointment;
- Those groups using offline channels,
- Groups with more specific accessibility requirements.

DNA engagement

Online journeys

Letters

Funding approach

Accessibility

A simplified journey for system users

Usability testing

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Research in alpha
what do you need

Alpha is where you [try out different solutions to the problems](#) you learnt about during discovery.

Spend alpha building prototypes and testing different ideas. And do not be afraid to challenge the way things are done at the moment: alpha is a chance to explore new approaches.

You do not have to prototype the user's entire wider journey.

You might not even want to prototype all of the transaction or elements you're working on: often it makes sense just to focus on the areas you think will be most challenging. This lets you do the minimum you need to test your riskiest assumptions.

Alpha services should not be available for the public to use.

You will need a multidisciplinary team to delivery your Alpha.

Product Management

Delivery Management

User Research

Content Design

Service Design

Technical Lead

Developer

Assisted Digital

Accessibility Lead

You will also need access to:
- a performance analyst
- a technical architect
- a web operations engineer
- quality assurance and testing skills

[set-up-a-service-team](#)