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Genotes – a 'just-in-time' genomics education resource co-designed with clinicians

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Abstract

Background Powerful new genomic technologies are transforming the way healthcare is delivered, shaping medical practice across all specialties. In this rapidly changing landscape, there is an urgent need to equip the clinical workforce with knowledge and skills to navigate the new healthcare terrain.

Co-design of healthcare resources with end users is increasingly gaining traction as a method of ensuring that educational content and delivery are tailored to users' needs, increasing likelihood of use and resulting in better outcomes for patients.

Here we describe the co-design and ongoing co-creation of GeNotes – an NHS England National Genomics Education flagship online resource providing genomics education at the point of patient care.

Methods To understand the barriers to implementation of genomic medicine and the training needs of the diverse NHS workforce, we adopted a co-design approach with clinicians from both primary and secondary care who are uniquely placed to understand the context in which they are working and identify their own training needs.

Concept design, initial user research and subsequent 'alpha' and 'private beta' phase user research was conducted in a series of co-design iterations employing a mixed methodology integrating quantitative and qualitative data collection and analysis.

Results User evaluation data demonstrated excellent feedback across the tested domains (content, navigation, likelihood of use and recommendation to colleagues). We identified several key themes from user testing that shaped the resource's development.

Conclusions The co-design approach to the development of this point-of-care genomics education resource for clinicians has allowed insight into the education needs, challenges and learning styles of end-users. The utility of this approach was supported by excellent user feedback across the tested domains, and we recommend it to others involved in developing healthcare resources in a fast-paced environment.

Keywords Co-design, Genomic medicine, Just-in-time, Education, Training, Primary care, Secondary care, NHS

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Background

Genomic medicine: A shifting landscape

Over the past two decades, game-changing new genomic technologies have transformed our ability to sequence and interrogate the human genome [1, 2]. With the evolution of this capability, the human genome can now be sequenced so fast and inexpensively that the use of genomic data for the diagnosis and management of disease is now a reality [3].

The fields of rare disease, prenatal diagnostics and oncology have already undergone a seismic shift and genomic medicine is rapidly becoming an integral part of clinical practice across all healthcare specialties [4].

Whole genome sequencing is now being undertaken as a routine diagnostic test in the NHS, with the world-leading 100,000 Genomes Project providing a springboard for the launch of the NHS Genomic Medicine Service – a national genomic testing service providing equitable access throughout England [4–8].

No longer the preserve of clinical geneticists, genomic testing is now being widely undertaken by clinicians from other specialties (so called 'mainstreaming') [4]. Clinicians who are not a part of the specialist genomics services ('mainstream clinicians') may lack experience in both requesting genomic tests and receiving and appropriately actioning genomic results. If the NHS is to deliver on the ambition to integrate genomic data across healthcare, there is a massive and urgent need to educate the healthcare workforce, from primary to tertiary care and across the medical and surgical specialties, about genomic technology, its potential, its challenges and its complications.

Key UK government strategies and policies have emphasised the need for a genomically literate workforce, with an understanding of how and where genomic testing fits into clinical pathways, and how to use it [9–14].

How prepared is the NHS workforce to rise to this challenge?

Several studies to date have addressed the current level of genomics education and training needs of the healthcare workforce [15–18]. A nationwide survey of the genomic training needs of UK oncologists found that formal training in genomics had not been received by 38.7% of oncologists, with 92.7% identifying a need for additional genomics training [15]. A nationwide survey of UK gastroenterology trainees found that only 9% and 16% of survey respondents believed that their local training programme adequately prepares them to use genomic medicine and personalised medicine, respectively [16]. A cross-professional training needs analysis of the whole NHS healthcare workforce found that between 75.9% and 85.7% (with variation by region) of healthcare professionals felt they needed further training in genomics [17]. When this cohort was asked about their preferred method of learning, there was a significant preference ($p<0.001$) for online over face-to-face learning.

A study addressing the particular genomics education needs of general practitioners highlighted that learning is most effective when it is clinical scenario-based, at point of care – so-called 'just in time' reactive learning [18]. Busy clinicians across all specialties struggle to find time to engage with proactive 'just in case' learning resources in genomics, so just-in-time learning (i.e. engaged with at the point of clinical need) represents an increasingly powerful approach.

Just-in-time resources have been shown to be particularly valuable in settings where there is a rapid pace of change, such as in the Covid pandemic, [19] to allow rapid dissemination of learning to bridge the second translational gap and swiftly incorporate evidence-based medicine into routine clinical practice.

Clearly, there is an urgent need to provide reliable online, just in time, genomics education, to support the multi-professional, multi-specialty NHS workforce with the constantly evolving training needs in genomics.

With the twin challenges of meeting the needs of a diverse workforce, in a constantly evolving landscape, it was decided that a genomics education resource to support clinicians should be designed in collaboration with key end-user stakeholders.

The co-design approach

Co-design describes a methodology whereby there is "meaningful involvement of end-users in the design process" [20]. In co-design approaches, resources are not just designed *for* users, but *with* users central to the design process, bringing invaluable insights as 'experts' in the context in which they practise, the challenges they face and their educational needs.

Co-design of healthcare resources with end users is being increasingly employed as a method of ensuring that educational content and delivery are aligned with users' needs [21–25]. This increases likelihood of uptake and sustainable use of a resource, [24, 26] leading to better outcomes for patients.

The approach adopted in the development of the GeNotes resource here described followed the framework of Treasure-Jones and Joynes [27], with each co-design iteration involving four processes (Analyse, Design, Develop and Test), with the insight gained at the end of each cycle providing the springboard for the next iteration of design work, as the resource evolved from conceptual discussion, through paper prototypes, to development and piloting of software prototypes.

Methods

Methodology and workflow

Concept testing, initial user research and subsequent 'alpha' and 'private beta' phase user research was conducted between May 2019 and October 2022 in a series of co-design iterations with clinicians from both primary and secondary care, employing a mixed methodology integrating quantitative and qualitative data collection and analysis. The workflow undertaken is summarised in Fig. 1.

Concept testing and initial user research

Concept testing and initial user research was undertaken to determine user needs, refine a content model, and identify technical constraints, opportunities and requirements for the creation, editing and maintenance of content for the resource.

A series of co-design sessions was held with prospective users, to understand user needs and envisaged constraints. Basic content prototypes were developed, and feedback sessions were conducted with end-users, comprising professionals from both primary and secondary care.

An initial content model for the service was developed, and a roadmap for service development established.

Alpha phase testing

Alpha phase testing was undertaken in line with Government Digital Service (GDS) standards (https://www.gov.uk/service-manual/user-research/user-research-in-alpha). This was run as a series of iterative sprints, with the development team collaborating to develop content and interface designs to then put in front of prospective users for feedback.

A prototype of the resource was built in the WordPress content management system. Moderated usability sessions of the pilot software prototype were held with clinicians from both primary and secondary care, with an additional group feedback session with primary care clinicians. Prototypes were iterated and refined in response this feedback.

Beta phase testing

Beta phase testing was undertaken in line with GDS standards (https://www.gov.uk/service-manual/user-research/user-research-in-beta). Working groups of clinicians with an interest in genomics from three specialties – oncology, paediatrics and primary care – were established. Working groups are multi-professional, multi-regional and multi-specialty, capturing the diversity of the workforce they are endeavouring to support.

Using the prototype templates refined during the alpha testing, a suite of resources was developed by the working group for each specialty, along with clinical scenarios designed to guide users to navigate through the resources to find the information required for the scenario. These were then used as a basis for extensive user testing.

Initial beta phase testing was undertaken as 'private' (i.e. with the website only accessible to those supplied with an access link) to avoid the resource being accessed and potentially used by clinicians whilst still in a prototype form. Testing sprints for the three specialties were

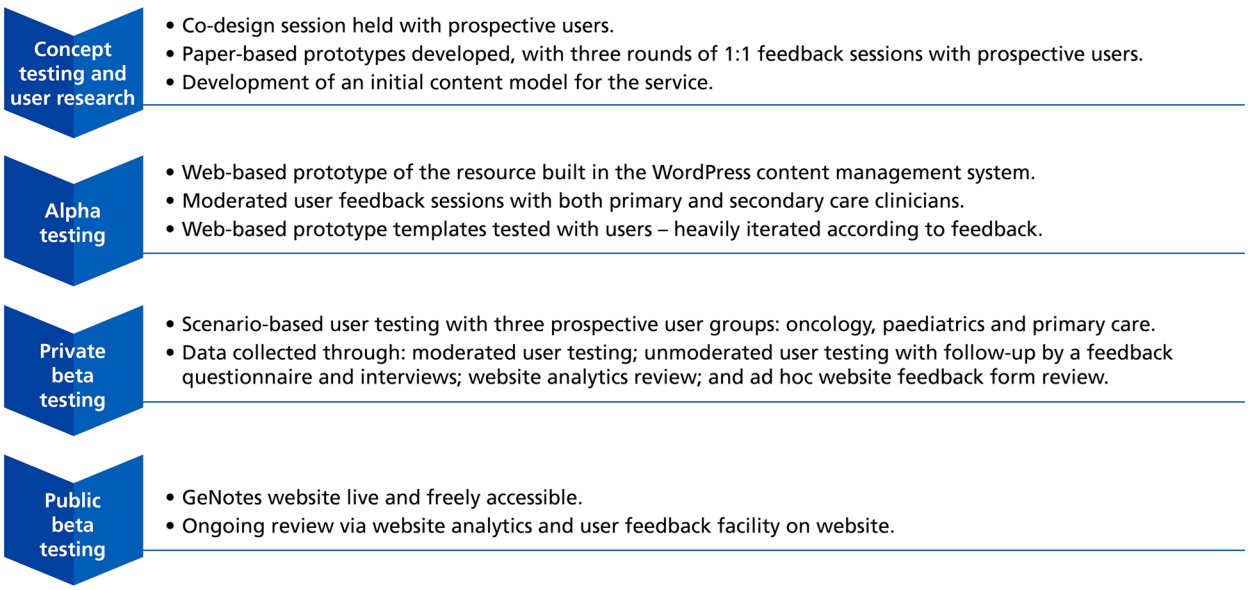

Fig. 1 Summary of workflow undertaken during design, development and user testing of GeNotes resource

conducted sequentially, with iteration of the resource between each sprint, according to user feedback. For details of the private beta user testing conducted for each professional group, see Fig. 2.

Accessibility audit

An 'accessibility audit' was undertaken, comprising 35 thorough tests covering all aspects of the Web Content Accessibility Guidelines (WCAG) (https://www.gov.uk/guidance/accessibility-requirements-for-public-sector-websites-and-apps) and recommendations to move towards accessibility compliance were actioned.

Participant recruitment and characteristics

Co-design participants were identified through the working groups' professional networks and through website and social channels.

Efforts were made to ensure that participants were representative of a variety of professional roles and settings, with varying seniority and genomics knowledge, and drawn from a wide geographical spread within the UK.

Data analysis

Quantitative data from the private beta testing feedback questionnaire across three professional user groups were gathered and analysed.

Additional qualitative feedback was gathered from moderated usability sessions and follow-up interviews and analysed to identify common themes and points of difference between the specialties.

Ethics

Formal ethics approval is not required for user testing among NHS colleagues for resource development and therefore was not sought. All research participants gave informed consent and were made aware of the organisation's privacy policy regarding storage and use of their data.

Results

During the iterative co-design process, we incorporated feedback from 1–2-1 concept prototype feedback sessions ($n=10$), alpha testing moderated user feedback sessions ($n=11$), private beta testing moderated usability testing sessions (oncology $n=5$, paediatrics $n=5$, primary care $n=3$) and questionnaire responses (oncology $n=21$, paediatrics $n=37$ and primary care $n=22$). Co-design participants were representative of a range of professional roles, settings, geographical regions and levels of genomics knowledge. Full details of characteristics of participants are supplied in Table 1.

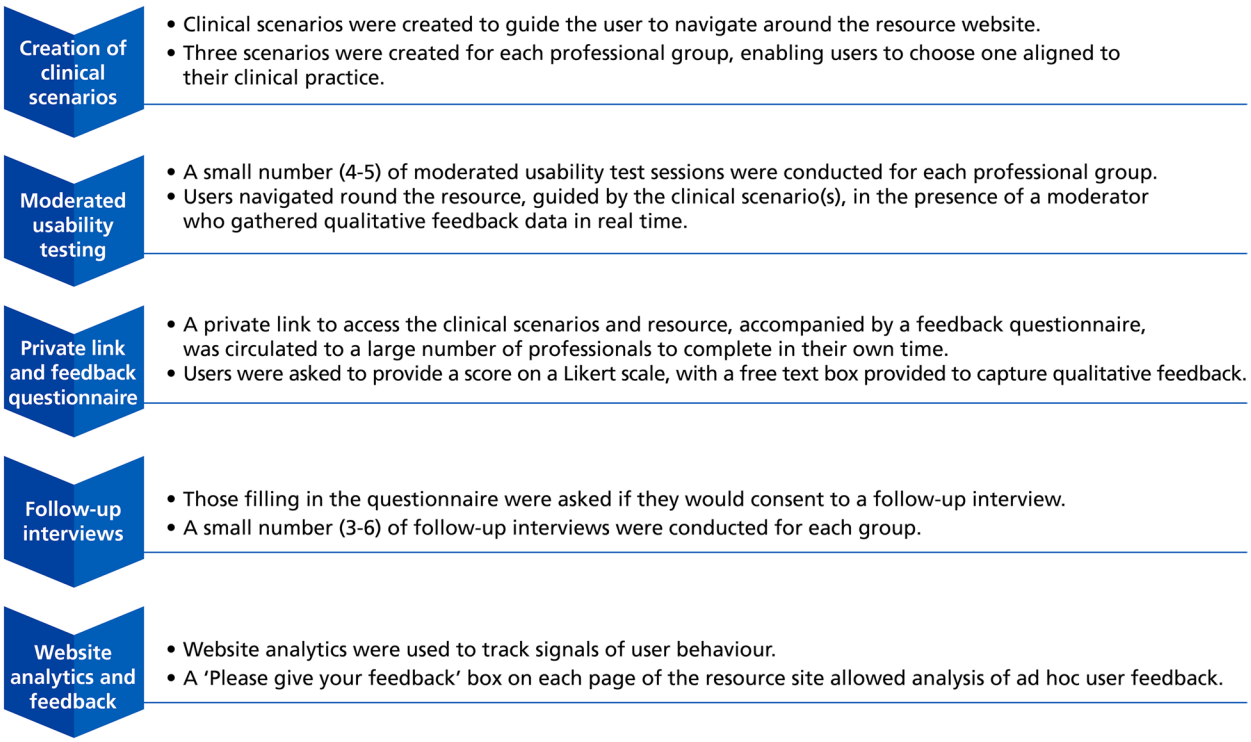

Fig. 2 Summary of workflow undertaken during private beta testing

Table 1 Characteristics of co-design participants

Session	Professional roles	Settings	Geographical regions
Concept and initial user testing			
1–2-1 concept prototype feedback session: Round 1 *n* = 4	1 GP 2 GP nurses 1 District nurse	Primary care	*
1–2-1 concept prototype feedback session: Round 2 *n* = 6	1 GP partner 1 GP trainee 1 endocrinology consultant 1 neurology consultant 1 oncology specialist nurse 1 neuromuscular specialist nurse	Mixed secondary and primary care settings	*
Alpha phase testing			
1–2-1 moderated user feedback sessions *n* = 11	1 paediatric oncologist 6 GPs 2 oncologists 2 paediatricians	Mixed secondary and primary care settings	*
Private beta phase testing—oncology			
Moderated usability testing sessions *n* = 5	2 consultants in medical oncology 1 doctor in training in medical oncology 1 doctor in training in clinical oncology 1 clinical fellow in medical oncology	3 district general hospital 2 specialist cancer hospital	2 NW England 1 NE England 2 London
Feedback questionnaire completed responses *n* = 21	10 consultants 6 doctors in training 5 other 13 medical oncologists 5 clinical oncologists 3 other	10 specialist cancer hospital 6 large teaching hospital 5 district general hospital	10 London 3 SE England 2 NE England 1 East of England 5 other
Private beta phase testing—paediatrics			
Moderated usability testing sessions *n* = 5	2 consultant neonatologists 1 doctors in training neonatology 1 clinical research associate paediatric rheumatology 1 doctor in training respiratory paedatrics	Secondary care	*
Feedback questionnaire completed responses *n* = 37	19 consultants 12 doctors in training 5 general paediatricians 6 community paediatricians 4 Neonatal intensive care 2 paediatric intensive care 2 other sub-specialties	8 community paediatric 13 secondary care 10 tertiary or quaternary care	5 London 7 SE England 2 NE England 3 East of England 6 NW England 4 Midlands 3 SW England 1 other
Private beta phase testing – primary care			
Moderated usability testing sessions *n* = 4	2 GPs 1 GP trainer 1 physician's associate	Primary care	*
Feedback questionnaire completed responses *n* = 22	18 GPs 1 practice pharmacist 1 lead midwife 1 physician's associate 1 other	Primary care	*

* data not available

Analysis of quantitative data from the private beta testing and qualitative data gathered throughout the co-design process identified several common themes and some points of difference between the specialties, presented here with representative comments from participants.

The current lack of a reliable information source and the need for efficient, reactive learning

Our findings demonstrated a genuine user need to fill gaps in existing knowledge and to keep up with the pace of change in the field, which was not being effectively met elsewhere. Users described that GeNotes

would be a more reliable replacement for their current method of checking information:

> *"I could see us using it in the clinic and before you see a patient. Otherwise you'd just be Googling it." Consultant, medical oncology, specialist cancer hospital*

> *"Whenever I get a tricky case, I just email my friend. Now there is a resource I can go and check instead." Consultant, medical oncology, large teaching hospital*

> *"I can't think of anything that is doing this job already so it will be really helpful to have." Doctor in training, paediatrics*

A theme that emerged strongly during the initial user testing and concept design phase was that of the extremely time-poor clinician, making a clinical management decision under time pressure, and the need for efficiency in accessing resources.

> *"You might only have 20 minutes with a patient where you've got to describe your treatment pathway, maybe some trials, and then you might have to look up GeNotes as well. It's got to be very intuitive, like holding you by the hand." Consultant, clinical oncology, specialist cancer hospital*

As such, a demand was identified for a resource that could be referred to quickly and easily, with the patient in the room. This clearly had implications for the planned structure of the resource, leading to the development of a provisional service sitemap, dividing content into two 'tiers':

Tier 1: 'In the Clinic'.

- Bespoke specialty-specific resources providing 'just in time' education for clinicians to support them in recognising clinical presentations with a possible underlying genomic cause, appropriately requesting or actioning the results of genomic testing, or making appropriate referrals.

Tier 2: 'Knowledge Hub'.

- Pan-specialty multimedia resources providing an underpinning encyclopaedia of genomics education.
- Accessed via relevant links from tier 1 resources to address knowledge gaps identified during clinical practice or directly to meet an education need.

Anticipated use of the resource – both to support clinical practice and as an education and training tool

User feedback highlighted anticipated use of the GeNotes resource for individual clinical practice, as a bespoke educational resource, and as a training tool:

> *"As a speciality trainee in oncology this is going to be a very useful resource in clinic and also for my own learning." Doctor in training, medical oncology, district general hospital*

> *"This was so useful and I would definitely want to use this and base some of our neonatal teaching around it." Consultant paediatrician*

> *"Exploring it and making it the focus of a tutorial – which I think would be a great tutorial for trainees." GP partner*

Content was considered well-structured and pitched appropriately, although users would value more visual content and patient communication aids

Ninety per cent of users 'strongly agreed' (26/80, 32%) or 'agreed' (46/80, 58%) that the content was pitched at the right level. Data for the three individual user groups are shown in Fig. 3a.

In the Clinic resources were valued for their concise, relevant clinical information and consistent clinical scenario-based format that enabled the efficient extraction of relevant information for time-poor clinicians at the point of patient care.

> *"It's very accessible, not overwhelming and very concise, it gives you the important information that you would need in the clinic." Consultant, medical oncology, specialist cancer hospital*

> *"I liked the same layout for the clinical cases, you knew exactly what you were going to get from that." Doctor in training, paediatrics*

> *"It is easy if you've just got literally 2 minutes to find out what you need to do, it was really easy." GP*

Some primary care clinicians suggested the Knowledge Hub contained more information than they needed, highlighting the difficulties of meeting the needs of a diverse group of clinicians in this pan-specialty part of the resource.

> *"We wouldn't be using that, we'd be interested in what are the results, what do I do with this? We're not so interested in the methodology of array CGH. I don't think most GPs would need this." GP*

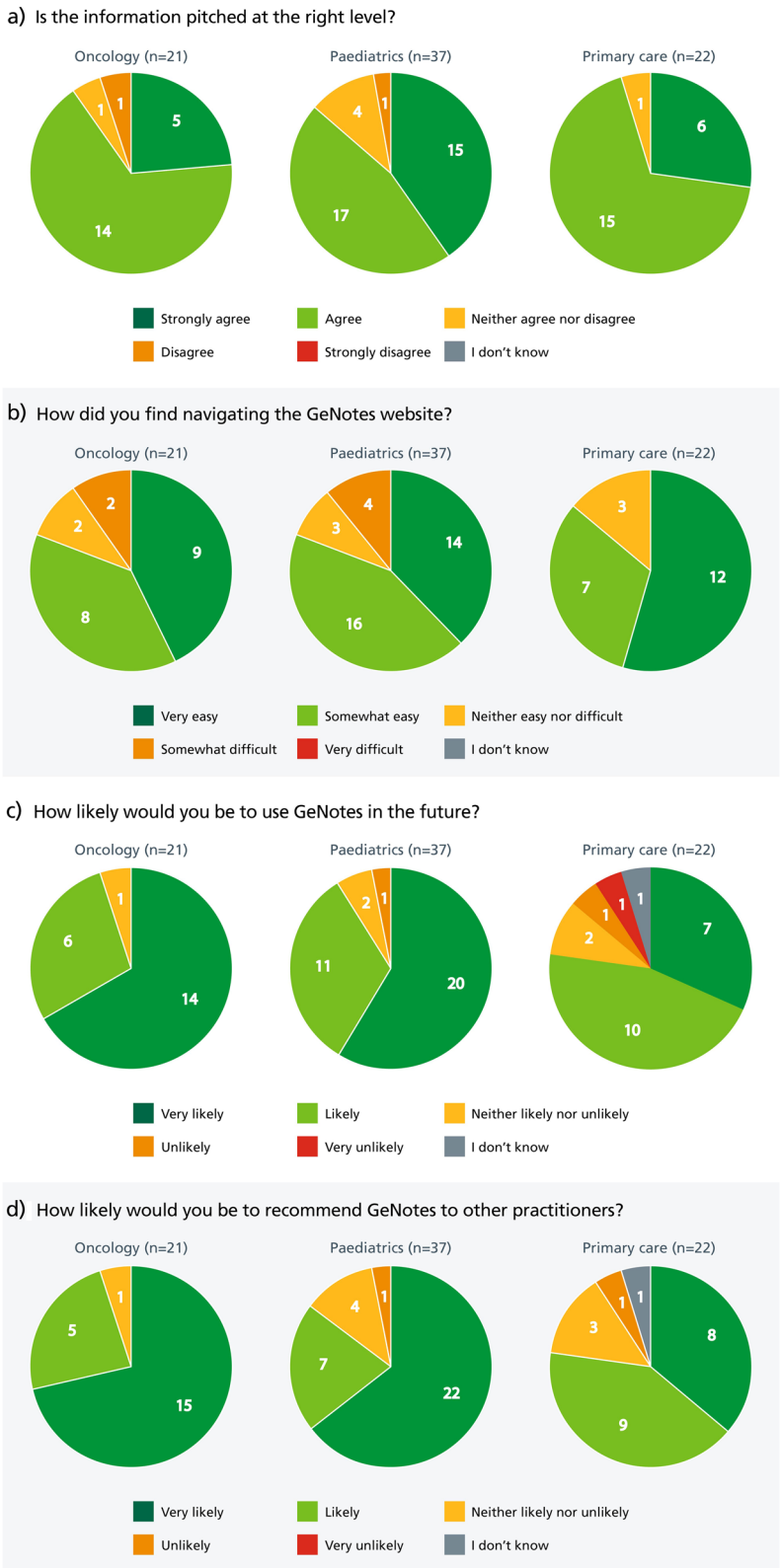

Fig. 3 Private beta testing quantitative data – (**a**) Content pitch, (**b**) Ease of navigation, (**c**) Likelihood of future use and (**d**) Recommendation to colleagues

Users expressed difficulties with processing lengthy amounts of text, and emphasised the value of a visual and multimedia approach to presenting information in the Knowledge Hub:

"I would benefit from more images as I'm quite a visual learner." Doctor in training, paediatrics

"More pictures/diagrams so not just reams of text." GP

"It's got things that apply to different styles of learners and different amounts of time that you've got." GP

Users emphasised the importance of reliable information and practical resources to support their communications with patients:

"Anything about what are the most relevant parts to tell people. What might the patient's family most want to know?" Doctor in training, paediatrics

Users perceived the resource as a trusted source and emphasised the importance of the content being kept up to date

Users expressed confidence in the resource, reinforced by the NHS branding:

"I think it's really good to have that checking resource you can trust." Consultant, medical oncology, large teaching hospital

"It's a trusted website, with the NHS logo." GP

Oncologists commented on the critical importance of the website being kept up to date, reflecting their practice in a particularly fast-moving field:

"It's fine to get yourself up to speed at one moment but you need to keep up to date with both new genomic features and new findings, new things we can do about it, like new drugs or new procedures." Consultant, medical oncology, large teaching hospital

Anticipated methods of access of genotes varied by specialty

The majority of users anticipated accessing GeNotes via desktop, laptop or mobile devices, with limited anticipated use via tablet (Fig. 4).

There was greater anticipated mobile use among secondary care physicians (oncologists and paediatricians) than general practitioners, reflecting their different working environments.

"Junior doctors don't have desks. They will be using a combination of a mobile device and a desktop computer, when they get a chance to sit down at one." Consultant paediatrician

"I'm all for getting this on a mobile, that would be great. Sometimes we do look things up quickly on a mobile in the clinic." Consultant, clinical oncology, specialist cancer hospital

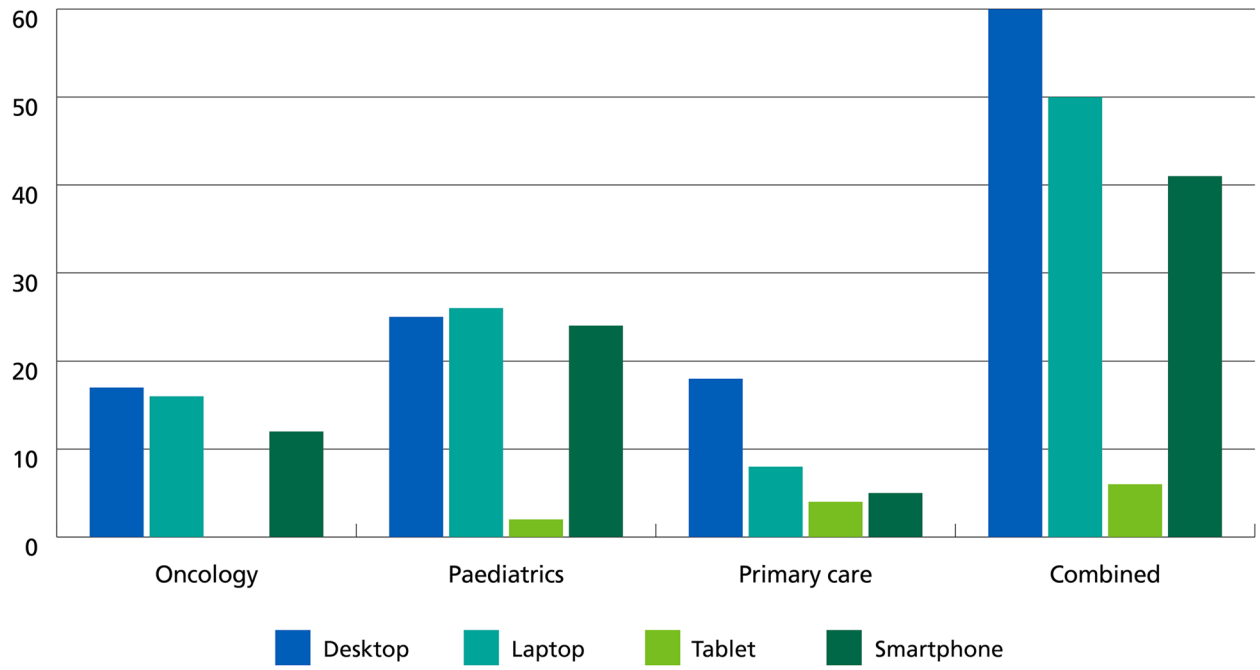

Fig. 4 Private beta user testing data – Anticipated route of access to GeNotes in the clinical setting

"I might use it as an app, but probably not as much as desktop and laptop." GP partner

Primary care clinicians highlighted the importance of any resource being compatible with their existing patient management systems (e.g. SystmOne/EMIS), resulting in a decision to build in an API (application programming interface) to allow syndication of content. This could allow primary care physicians to be supported with relevant content at particular points in patient pathways.

"It would be easier to access information on my clinical system, rather than open up another website on another screen." GP

"I've got my Primary Care IT system up here, so ideally what I'd want to be able to do is access it from whatever system I was on. Even if that was just a hyperlink." GP

Secondary care physicians were less concerned about the resource's online location, mainly due to the diversity in secondary care systems used across different hospitals.

"There's not one system. Often hospitals have their own resources generally. Ideally each Trust would have to put this on their own intranet or something like that." Oncologist

Users expressed a need for GeNotes to provide support with using the National Genomic Test Directory [8] (the full directory of genomic tests available to NHS patients in England).

"The bit where I look for the R number, that requires me to look on a link. That was the bit where I came unstuck when I did something like this recently." Consultant paediatrician

"Ideally this resource is what should tell the clinician that the child is eligible for testing rather than expecting the user to go somewhere else as well." Consultant paediatrician

The resource was easy to navigate and find information, although the search function needed improvement

Eighty-three per cent of users found it either 'very easy' (44%, 35/80) or 'somewhat easy' (39%, 31/80) to navigate the GeNotes website (Fig. 3b).

Overall usability of the resource was assessed using the System Usability Scale, [28] – a set of 10 questions designed to give an overall usability score for a digital resource. The aggregate score across the three user groups was 89 (oncology 90, paediatrics 86, general practice 91). This can be compared with a mean average score for digital services of 68 [29].

"Everything was where I'd expect to be, it didn't take too many clicks or sub-menus to find what I was looking for." Doctor in training, medical oncology, district general hospital

"Easy to find what you wanted with clear sub-divisions and headings." Consultant paediatrician

"I looked at all three scenarios – again all easily navigable. I found the information." GP

Although the feedback on navigation of the resource was generally positive, the search function on the private beta website was basic at the time of testing and users emphasised the importance of having a smarter search functionality:

"I couldn't find heart disease by typing cardiac, which would be a common way of searching for this." Doctor in training, paediatrics

"What google does well is that if you mistype the words it would still pull them up. If it came up with suggested searches as you type it in that would be great." Doctor in training, paediatrics

Oncologists were also keen to filter by topic (e.g. cancer type):

Table 2 Summary of next steps

• Explore integration with National Genomic Test Directory
• Formalise pipeline for resource update and review, both regular and ad hoc
• Develop bespoke proactive learning journeys according to clinical pathways/curricula
• Develop visual and multimedia aspects of Knowledge Hub expanding use of images, figures, infographics, animations, narrated presentations and videos
• Scope the potential development of a GeNotes mobile app
• Integration into clinical systems, e.g. primary care patient management system
• Develop smarter search functionality, e.g. flexible search terms and query suggestions
• Expand resource content – support and formation of more working groups
• Ongoing public beta site evaluation via website analytics and feedback tab
• Launch of 'gold' site, following satisfactory completion of private beta phase

"The search function worked but my logic was expecting there to be a drop-down menu by tumour type with the search function as a fall back." Consultant, medical oncology, large teaching hospital

Users anticipated future use of genotes and were likely to recommend it to colleagues

Eight-eight per cent of users were either 'very likely' (53%, 41/77) or 'likely' (35%, 27/77) to use GeNotes in the future (Fig. 3c) and 86% were either 'very likely' (58%, 45/77) or 'likely' (27%, 21/77) to recommend GeNotes to other practitioners (Fig. 3d).

"Am I likely to use it in the future? Definitely, 100%" Doctor in training, medical oncology, district general hospital

Discussion

Employing a co-design approach in the development of this genomics education resource for clinicians allowed crucial insights from the outset into the challenges clinicians face following the genomics revolution, and their training needs to navigate this dynamic landscape.

In the evaluation phase, user testing data justified our confidence in this approach, demonstrating excellent

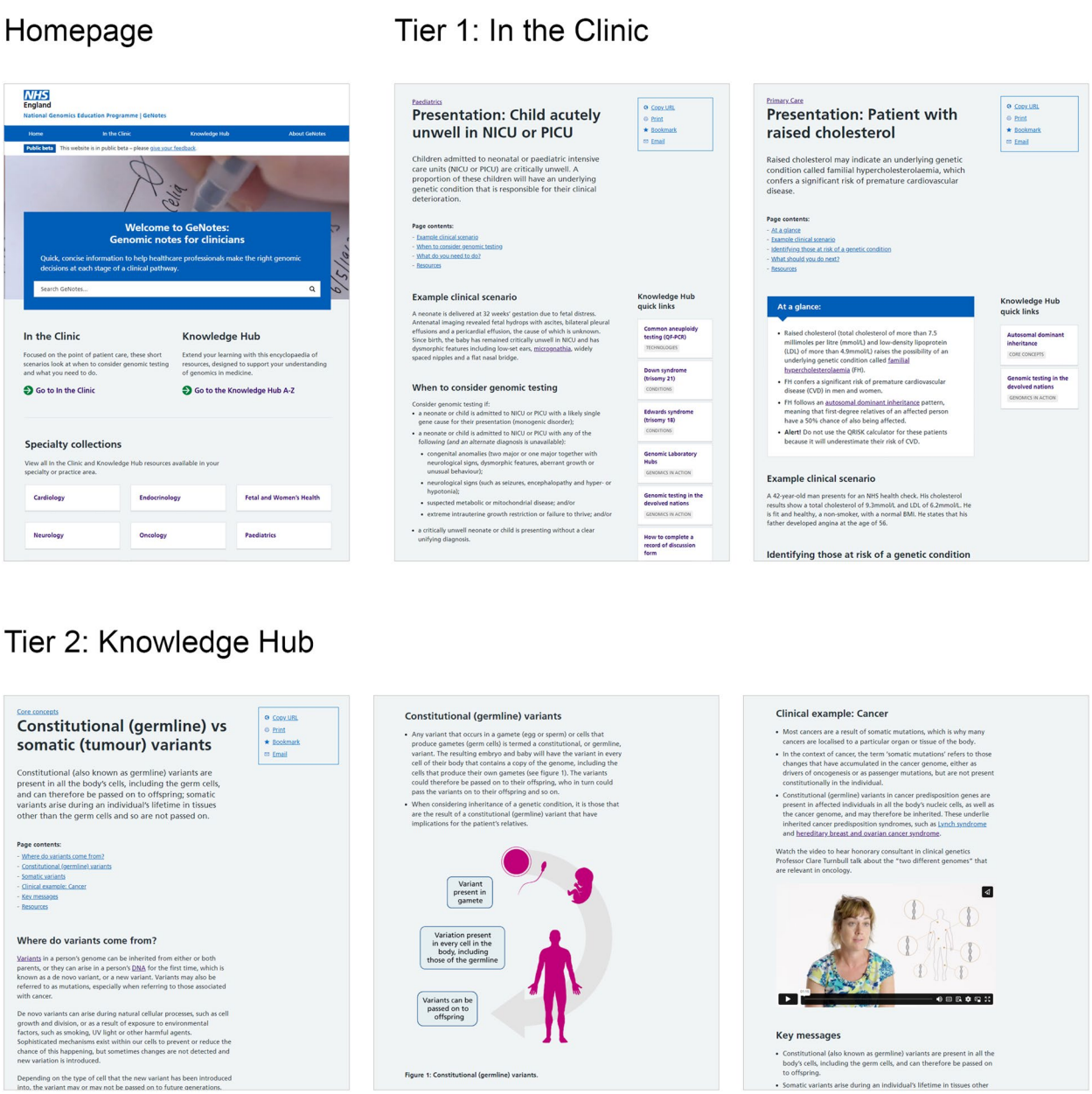

Fig. 5 Images from the GeNotes website showing homepage and examples of 'In the Clinic' and 'Knowledge Hub' resources

feedback across the tested domains (content, ease of navigation, and likelihood of future use and recommendation to colleagues).

Feedback from users suggests that there is no existing openly available resource that is meeting clinicians' need for just-in-time genomics education. Previous methods of accessing information included emailing colleagues and using internet searches, with no guarantee of the quality and reliability of the information. In contrast, users perceived GeNotes as a trusted resource and were reassured by the NHS branding.

The need for up-to-date information – especially by oncologists, who operate in a particularly fast-moving clinical landscape – was emphasised. Users valued reassurance that GeNotes' pages are being regularly reviewed and updated, with 'Last updated' information flagged.

Users valued GeNotes as a resource for their own individual learning, but also saw its potential as a training tool. The pan-specialty, encyclopaedic Knowledge Hub resources can be accessed via relevant links from 'In the Clinic' resources but can also be accessed standalone. It is anticipated that in future these resources will be assembled like 'mosaic tiles', to create bespoke learning journeys aligned to clinical pathways, curricula and other training needs.

The co-design process and end-user evaluation has provided many insights into what clinicians currently value about the GeNotes resource and how to direct efforts to improve the resource and user experience. For a summary of the next steps identified as a result of the user testing, see Table 2.

Expanding the resource content – from co-design to co-creation

This project has evolved from a co-design approach, to one of true co-creation [30]. GeNotes content is developed *by* clinicians *for* clinicians. Resources are authored and reviewed by specialty working groups (WGs), with multi-professional and multi-regional members, who are ideally placed to understand the needs of their colleagues. GeNotes is underpinned by robust governance, long term funding, content development and administrative support, ensuring that the resource is sustainable, regularly updated, and can grow and respond to need and innovation.

The first GeNotes content was launched on the public beta site in June 2022, with several other WGs since launching content, and more in formation. Images from the website with examples of both 'In the Clinic' and 'Knowledge Hub' resources are shown in Fig. 5. GeNotes is open access and freely available to clinicians, [31] and subject to ongoing review via website analytics and user feedback forms. This data will provide real-world insights into how and when GeNotes is being used, and the user experience.

At the time of writing, GeNotes has been accessed by over 140,000 users from 99 countries, receiving in excess of 280,000 total page views, with a rapid month-on-month increase in visitors to the site.

Conclusions

Here, we describe the co-design and co-creation of the GeNotes genomic education resource *by* clinicians, *for* clinicians. We anticipate that this approach will have relevance and utility for other educators attempting to meet the needs of a diverse set of end-users in similarly fast-moving fields.

Abbreviations

GDS Government digital service
WG Working group

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Authors' contributions

AF, AK, MB, EC, EH, JH, EH, TMV and KTB made substantial contributions to the conception and design of the work and the acquisition, analysis and interpretation of data. DB, LG and SS made substantial contributions to the analysis and interpretation of data. AF wrote the manuscript. All authors revised it critically for intellectual content, approved the final draft and agreed to be accountable for the work.

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None to declare.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Formal ethics approval is not required for user testing among NHS colleagues for resource development and therefore was not sought. All research participants gave informed consent and were made aware of the organisation's privacy policy regarding storage and use of their data.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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