

**Co-design of digital learning resources for care workers:
reflections on the neurocare knowhow project.**

SORENY, Catherine <<http://orcid.org/0000-0002-6980-3982>>, TAKHAR, Philippa <<http://orcid.org/0000-0001-6163-9041>>, VICKERS, Emma, BARTLETT, Rebecca, COATES, Elizabeth, STAVROULAKIS, Theocharis <<http://orcid.org/0000-0002-3535-7822>>, FOX, Emily, DAVIDSON, Heather, HARRISON, Adam and MCDERMOTT, Christopher <<http://orcid.org/0000-0002-1269-9053>>

Available from Sheffield Hallam University Research Archive (SHURA) at:

<https://shura.shu.ac.uk/36952/>

This document is the Published Version [VoR]

Citation:

SORENY, Catherine, TAKHAR, Philippa, VICKERS, Emma, BARTLETT, Rebecca, COATES, Elizabeth, STAVROULAKIS, Theocharis, FOX, Emily, DAVIDSON, Heather, HARRISON, Adam and MCDERMOTT, Christopher (2022). Co-design of digital learning resources for care workers: reflections on the neurocare knowhow project. *Journal of medical engineering & technology*, 46 (6), 518-526. [Article]

Copyright and re-use policy

See <http://shura.shu.ac.uk/information.html>



Co-design of digital learning resources for care workers: reflections on the neurocare knowhow project

Cathy Soreny, Philippa Takhar, Emma Vickers, Rebecca Bartlett, Elizabeth Coates, Theocharis Stavroulakis, Emily Fox, Heather Davidson, Adam Harrison & Christopher McDermott

To cite this article: Cathy Soreny, Philippa Takhar, Emma Vickers, Rebecca Bartlett, Elizabeth Coates, Theocharis Stavroulakis, Emily Fox, Heather Davidson, Adam Harrison & Christopher McDermott (2022) Co-design of digital learning resources for care workers: reflections on the neurocare knowhow project, *Journal of Medical Engineering & Technology*, 46:6, 518-526, DOI: [10.1080/03091902.2022.2089253](https://doi.org/10.1080/03091902.2022.2089253)

To link to this article: <https://doi.org/10.1080/03091902.2022.2089253>



© 2022 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.



Published online: 19 Jul 2022.



Submit your article to this journal [↗](#)



Article views: 1112



View related articles [↗](#)



View Crossmark data [↗](#)



Citing articles: 1 View citing articles [↗](#)

Co-design of digital learning resources for care workers: reflections on the Neurocare Knowhow project

Cathy Soreny^{a,b,c} , Philippa Takhar^{d,e} , Emma Vickers^a, Rebecca Bartlett^f, Elizabeth Coates^g, Theocharis Stavroulakis^g, Emily Fox^h, Heather Davidson^h, Adam Harrison^h and Christopher McDermott^{i,d,e} 

^aOptical Jukebox Ltd., Bristol, UK; ^bCulture and Creativity Research Institute, Sheffield Hallam University, Sheffield, UK; ^cNorthern Care Alliance NHS Foundation Trust, Manchester, UK; ^dNIHR Devices for Dignity MedTech Co-operative, Sheffield, UK; ^eSheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK; ^fAmmba Digital Ltd., Birmingham, UK; ^gSchool of Health and Related Research, University of Sheffield, Sheffield, UK; ^hNeurocare KnowHow, Sheffield, UK; ⁱDepartment of Neuroscience, Sheffield Institute for Translational Neuroscience (SITraN), University of Sheffield, Sheffield, UK

ABSTRACT

Neurocare Knowhow is an online learning platform for care workers who support people with neurological conditions. Care workers often do not receive specialist training around neurological conditions and can experience anxiety and apprehension about caring for this group. Neurocare Knowhow aims to increase care workers' knowledge and confidence. Featuring flexible and personalisable digital features, in combination with documentary video and audio, it offers an alternative to traditional e-learning, moving away from longform didactic courses to flexible on-the-go learning. This co-design project worked closely with people with neurological conditions, their families, care workers and care organisation managers to validate the need and develop a proof of concept pilot. Co-design activity took place across multiple workshops in person and online. These gathered detailed insights into preferred features that support engaging online learning. The platform offers learning across diverse neurological conditions as a whole, with a focus on shared symptoms and challenges encountered by people with neurological conditions. Ongoing development to scale the pilot up to meet an anticipated national audience includes a focus on artificial intelligence to support searches at a moment of need and a range of personalisable features for individual and team learning.

ARTICLE HISTORY

Received 12 November 2021
Revised 13 April 2022
Accepted 8 June 2022

KEYWORDS

e-Learning; care worker; personal assistant; co-design; neurological conditions

1. Introduction

Neurocare Knowhow is a co-designed online learning platform for care workers who support people with neurological conditions (pwNC) in the community, with the aim of increasing care workers' confidence and knowledge. The platform offers symptom-led learning content, enabling learners to understand key principles of care and take these skills with them to diverse clients, in diverse care contexts. This participatory project has involved close collaboration with people with neurological conditions, their families and care workers to evolve the concept, learning content and digital technology approach.

Neurocare Knowhow (NCKH) offers an alternative to the traditional long-form, linear e-learning models which typically offer a predefined "one-way" course

structure. NCKH takes an innovative approach offering flexible "non-linear" learning materials on the go, affording readily accessible "just-in-time" knowledge, with cues to deeper-dive learning that fit around care workers' busy and often unpredictable schedules. NCKH's approach to learning offers real life insights, through short form documentary video and audio, co-created with pwNC and care workers, affording learners realistic and relatable insights into daily care activities.

This paper reports on progress to date across the validation stage (2019) and current proof of concept stage (2020 to early 2022) and reflects upon the evolution of our cross-disciplinary co-design approach to creating flexible online learning resources. It also outlines aims for next-stage development towards offering a nationally available learning platform at scale to meet the needs of the community and care sector.

CONTACT Cathy Soreny  cathy@opticaljukebox.org  Optical Jukebox Ltd., Bristol, UK

© 2022 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

2. Background

The initial motivation for NCKH arose during the making of the myMND project, a previous collaboration between the project partners. This award-winning learning platform (www.mymnd.org.uk) offers video-led patient information resources to support people with motor neurone disease (MND) who are facing difficult choices around treatments for breathing and nutritional support [1]. The project involved co-design activities with a group of people with MND and their families. During the workshops, and when filming in people's homes, the team were often coincidentally told about people's experiences with paid care provision. Issues around continuity of care and care workers' unfamiliarity with neurological conditions and symptoms were a common experience. When reflected back to the clinical project partners they recognised this anecdotally as an ongoing issue. Awareness of the complex working conditions experienced by care workers led us to explore factors contributing to these issues and stressors, and ultimately evolved into the concept for Neurocare Knowhow.

2.1. Neurological conditions

The focus of NCKH is on improving care worker's knowledge and confidence in supporting pwNC. A neurological condition is any condition affecting the brain, spinal column or peripheral nervous system. Data published by Neurocare Alliance in 2019 [2] indicates rising prevalence of neurological conditions in England, with an estimated 14.7 million neurological cases (1 in 6 people), including an estimated 150,000 people with a rare neurological condition. There are over 600 different neurological conditions [3] and many people have multiple diagnoses. The Neurological Alliance Patient Experience Survey 2018/19 [4] found neurological conditions affect quality of life, with 46% of respondents reporting this to a "great extent" (most severe option) and 35% to a "moderate extent".

People with neurological conditions have a broad range of experiences around symptoms and how these impact upon daily life. People with the same condition may have a very different presentation. There may be variation in progression, how much activities of daily living are affected; some conditions are life limiting. This is reflected in the level of support people may need to support independent living. Despite the high prevalence of neurological conditions in the population, this diversity of conditions and variation in individual experience can be a challenge in delivering

quality care provision. The "Transforming Community Neurology" report [5] describes a sense of "neurophobia" among non-specialist care workers – anxiety experienced by care workers of all levels who due to lack of learning opportunities feel that neurological conditions can be unpredictable and complex to manage. The report highlighted a lack of knowledge and skills that has had a profound impact upon the physical and mental health of pwNC, and the recommendation that upskilling of carers was essential.

Provision of appropriate neurological support is essential. For example, research conducted by the Sue Ryder Charity [6] estimates that in 2019, 15,143 people with a neurological condition were resident in a non-specialist older people's nursing or care home in England, concluding that this population were potentially not receiving the specialist care appropriate for the complexity of their conditions. The training of care workers to empower them to deliver quality and appropriate support with confidence is key, as is the support from care organisations to foster and encourage team learning and change.

2.2. Care workers as target learners

The intended learners who will access NCKH are care workers from across three main care settings – care home workers, domiciliary care workers and personal assistants (PAs), who provide support to pwNC as part of their everyday work. The authors recognise that each of these worker groups have differences in their roles and remit, but for simplicity across this paper they are referred to by the umbrella term "care workers".

These learners are part of England's social care workforce of over 1.54 million [7]. Within the adult social care sector there is a high turnover of care workers, with average levels of 34.4% in 2020/21 [7]. The reasons for care workers leaving roles, or the care sector, are multifactorial. To identify best practice strategies to improve workforce retention, Skills for Care consulted with care organisations with a staff turnover of less than 10% and found that investment in learning and development had been one of the key factors in their workforce retention [8]. The lack of a career pathway for care workers is felt to contribute to retention issues, with a programme of learning that focuses on offering flexible learning that fits around the working day, and with a focus on supporting people with long term conditions [9].

2.3. Traditional e-learning

E-learning can be defined as learning using the internet and a personal computing device as its mode of delivery [10]. Within vocational learning for the social care workforce e-learning is frequently used instead of classroom based activity, as it provides greater flexibility for *when* a learner engages in training and has less impact on staffing cover [9].

However, e-learning has been seen by some as a “lonely, individualising and sterile learning experience” [11]. Lewis et al. [9] found that learners can find it harder to contextualise their learning when done online compared to blended approaches that include in-person elements, and expressed a preference for “on site, hands on” learning, over e-learning completed away from the care setting. The need to explore approaches towards online learning that offer shared learning, contextualisation, and flexibility around the working day would address the needs of managers and learners, and help improve engagement with learning. Better integrated, ongoing training is also beneficial from the perspective of pwNC being supported as well.

2.4. Unmet need

NCKH aims to offer flexible online educational support to care workers to develop their knowledge and confidence when supporting pwNC. Recognising the diversity of conditions and individual progression, it adopts a symptom-led approach to learning content. It offers potential for use across various care roles and contexts. The project addresses the needs of pwNC and the care workers who support them, whilst seeking to explore innovative new approaches to e-learning.

3. Approach

The project team is an interdisciplinary collaboration that includes diverse partners - research and healthcare (University of Sheffield), technology development for people with long-term health conditions (NIHR Devices for Dignity MedTech Co-operative), digital architects and platform creators (Ammba Digital) and healthcare filmmakers and writers (Optical Jukebox). This mix across creative, technology and healthcare expertise strongly informs the team’s working processes. All partners have a track record in participatory and co-design approaches, and the NCKH project reflects the ongoing evolution of this ethos.

The foundation for NCKH is the myMND project. During this, three online patient information platforms

were created, co-designed with people with MND, their families, care workers and specialist health care professionals. As this project evolved through its iterations, so did the ethos of the learning materials produced. One participant Terry spoke vividly in workshops about how he delayed having a feeding tube fitted for many months, due to fear of the unknown. He wished he could have met someone who had a feeding tube early on, to help him understand what it might be like. This insight shifted the project’s approach from expert-led learning, towards a peer-led learning model. Co-created documentary videos featured real-life role models, with similar experiences of the same issue.

The key learning from the myMND project was the strength of the co-design process to develop highly relevant and engaging learning content, and the power that co-created real-life video footage has to support learning. Evaluation feedback on the myTube platform showed that it has supported people to make complex and emotional choices around their care [1]. To further evolve this approach across the NCKH project the process has drawn upon the constructivist model of education and the social model of disability. The social model views disability as the limitation of opportunities for equal participation in life due to physical, social and design barriers [12,13] and has grown from disability rights and activism movements in the UK and US. This model has informed a holistic approach to the content that focussed on supporting independence over task-orientated care.

Constructivist education approaches focus on creating learning environments that support learners to construct their own meaning in relation to learning materials [14] making relevant connections to their own practice. Co-design offers an approach to participatory knowledge generation in healthcare that offers a “political and sociocultural mindset shift from ‘experts know and decide everything’ to ‘we need to decide things together’” [15, p. 247] that supports pwNC and their care workers to be central in creating an engaging, relevant learning platform that responds to the unmet needs of these groups.

4. Project

4.1. Validation stage

Across three in-person co-design workshops we engaged with a range of stakeholders, who offered us a detailed and nuanced insight around the key issues of concern. Additional telephone interviews were also conducted with pwNC who were unable to attend the

Table 1. Background of co-design participants in the validation stage.

- 4 People with motor neurone disease, cerebral palsy, functional neurological disorder and Huntington's disease
- Their families (2 spouses, 1 parent, 1 sibling)
- 5 Care workers from a care home group (some with previous experience of domiciliary care)
- 2 Care home managers
- 2 Care managers employed by a local authority
- 2 Care managers from a national neurological charity
- 1 Regional representative from another national neurological charity
- 1 Representative from local specialist neurological community service
- 1 Representative from local further education college health and social care faculty

Table 2. Relevant themes from analysis of workshop one and interviews.**Key issues for pwNC and families**

- Care workers' knowledge of neurological conditions not always strong
- Seeing beyond the condition and recognising individual differences
- Importance of 'soft skills' as foundation for other skills

Key issues for care workers and care organisations

- High staff turnover across sector for multiple reasons
- Training focus on generalist skills, rather than specialist e.g., neurological
- Fear of the unknown and possible consequences of limited knowledge
- Need for access to reliable and quality information resources

workshops. This resulted in a diverse group covering a range of roles and contexts (Table 1). They were approached through networks and charities known to the project team.

Workshop one focussed on understanding/exploring the perceived skills needed to support pwNCs and the related challenges faced by care workers. The group were shown webpages and video content from the myMND project and this was discussed in relation to the proposed approach. The group discussion showed a good acceptance of the proposed concept of symptom-based learning, through documentary video-led content delivered via a flexible online platform. When discussing potential topics and content the group focussed on broader principles of care, beyond discrete care tasks, and leading to deep reflections on the potential ethos of the learning platform. Multiple themes emerged around barriers to delivering quality care (Table 2).

This led into a scoping exercise on current learning formats, incentives and barriers, and exploration of what makes learning engaging. Current e-learning approaches were viewed with some scepticism by the group, based around perceptions of it typically being lengthy, inflexible, sometimes out of date, and therefore "tedious" to complete. The learning from these types of courses could be hard to recall later when back in practice. Elements that improved e-learning were use of visual material and videos, and the opportunity to learn alongside peers. There were several

Table 3. Preferred features for learning platform and content.

- Use of various media to suit different learning styles
- Use of video and images materials alongside text
- Real-life scenarios to help make connections with own practice
- Prefer documentary videos, not acted scenarios
- Recreate feeling of working alongside/shadowing experienced peers
- Audio files to offer alternative approach to learning when time limited
- Video and audio length - generally aim under 2 min
- More flexible structure for accessing learning materials
- Shorter chunks of learning to fit around practice as needed during the day
- Opportunities for group interactions around learning

elements that the co-design group highlighted for engaging learning (Table 3).

Workshop two reflected these themes and ideas back to the group for working towards an initial concept for a platform structure and selecting ideas for filming themes. Building upon this, a draft structure for the platform was created that demonstrated potential navigation of the platform through the key themes. Filming took place at a specialist neurorehabilitation care home with care workers who had participated in the workshops, plus residents with Huntington's disease and traumatic brain injury. The video and audio clips were edited in different styles to explore possible approaches. They captured interactions between residents and care workers, as well as "top tips" for communication. The website design and audiovisual content were presented to the wider group at workshop three. There was a positive response to the proposed website design, and mixed reactions to the different editing/filming approaches used. The contributions gathered from this feedback helped shape the next stage of development and filming.

4.2. Market research

The aim is for Neurocare KnowHow to become a not-for-profit, commercially viable training offer for a diverse range of care organisations (through dedicated training budgets) and individual employers of PAs (through direct payments). A market research report was commissioned [16] from Learning Light consultancy to assess current e-learning provision around neurological conditions and gain a deeper understanding of customer demand.

Social care providers are served by a large number of e-learning vendors. Learning Light undertook an analysis of thirty vendors, reviewed the range of courses offered, and critically assessed their quality and educational approach. The key findings are summarised (Table 4). There was a focus on compliance

Table 4. Key market research findings – e-learning provision.

Design and approach

- The market is characterised as one of compliance and qualification
- Courses focus on passing assessments rather than changing behaviours
- Courses predominantly of a dated design (e.g., using Flash software)
- All but one (not fully launched) offer longer form modules with a linear structure

Use of video

- Limited use of video across providers
- Typically narration led in style, with a presenter representing an expert perspective
- Often visually unstimulating, with simple animations or graphics
- Reliance on text on screen being read aloud by presenter
- Scenarios with actors that often seem stilted or employ stereotypes

Coverage of neurological conditions

- The market for neurological-specific online learning is poorly met
- No vendor currently offering a suite of courses around neurological conditions

and completion, as opposed to changing behaviours through more in-depth learning approaches. Neurological conditions were underserved with resources focussing on awareness, not offering deeper insights around ongoing support. The resources reviewed were often of an older digital design and the video content typically was didactic, presenter-led and on occasion utilised stereotypes for re-enacted care scenarios.

A market analysis showed there were no direct competitors to NCKH covering neurological conditions. Indirect competitors were either focussed upon in-person training or offered more general awareness raising content using didactic video content. The research suggests that there is a market opportunity for an innovative neuro-specialist learning platform, offering a more flexible course structure, populated by content that offers more realistic and empathetic insights into care scenarios, whilst also meeting the needs of care service managers to show development of their workforce.

4.3. Proof of concept stage

Building upon the insights from the validation stage and market research, prototype development is occurring over two agile co-design cycles, and at the time of writing the project is nearing the end of co-design cycle 2. These co-design cycles comprise iterative development of different forms of learning content; technical development to create a scalable platform; and user testing of the prototype to inform next-stage development and the market access strategy. The aim is to explore and evaluate approaches to content development and digital technology on a small scale, to effectively co-create a “blueprint” that can be scaled up at the next stage.

Table 5. Background of co-design participants in the proof of concept stage.

- 1 Person with cerebral palsy with 2 PAs from their live-in team
- 1 Person with cerebral palsy with their PA (also receives home care visits)
- 1 Person with MSA, their spouse, their PA and 2 home carers
- 1 Person with Huntington’s with 2 care workers from their residential home
- 1 Person with Parkinson’s considering starting care soon
- 1 Spouse of person with multiple sclerosis, had chosen not to have care workers
- 2 Care workers from a specialist neuro care home
- 1 Training manager from a care home group (previous care worker in home care and care home)

The project commenced in August 2020. Due to the Covid pandemic, the project design was swiftly adapted to work within online spaces, which offered advantages of accessibility for those with disabilities and from geographically diverse locations, but also slowed content production and evaluation activity.

4.3.1. Co-design process

Co-design cycle 1 started with online co-design workshops with a diverse group of stakeholders (Table 5). These people were recruited nationally via charities, support networks, care home groups, personal assistant register and social media posts. In-depth facilitated discussions around people’s lived experiences of “communication difference” and “movement and mobility” themes enabled capturing of key issues. These insights were developed into ideas for videos and mini podcasts, and informed the digital platform development.

Several participants from this group were keen to be involved with filming, and further co-design storyboarding workshops took place between the filmmaking team and the pwNC, families and care workers involved. Due to Covid, the team were unable to film in person with the participants over winter 2020/21, so online support and training was given to enable self-filming and recording. Footage and audio was gathered for editing, and several short films and mini podcasts were produced. Alongside the filming process, the digital platform was developed, building upon the “wish list” of features from the validation stage, and refined further in response to group discussions in cycle 1. The videos, audio and accompanying text and images were uploaded to the platform as an early draft of potential ideas and sent out to the co-design group for evaluation and feedback.

Co-design cycle 2 began with further co-design video calls with the project participants. This involved discussion around their questionnaire feedback, and planning for more filming to add to existing footage.

Table 6. NCKH platform learning themes.

-
- Supporting independence
 - Building rapport
 - Communication difference
 - Movement and mobility
 - Personal routines
 - Nutrition and eating
 - Comfort and managing pain
 - Breathing support
-

Feedback from the wider group enabled reflection on which video, audio and text approaches were working best, what to try out next, and how the digital design could be improved to support this.

4.3.2. Learning pathways

The symptom-led approach offers learning relevant to multiple neurological conditions. The symptom-based themes have been evolved with the co-design groups during the validation and proof of concept stages. The social model of disability has informed this by focusing upon holistic support for independence, rather than completion of care tasks (Table 6). For the proof of concept stage, the focus has been to create content around “communication difference” and “movement and mobility”. The content and technology work together to offer flexible learning pathways, drawing learners towards relevant content, so they can build a bank of knowledge that is most useful to them. Different content and technology “blueprints” for learning are being trialled to best fit learner needs, and evaluated across the two cycles of co-design.

4.3.3. Learning content

The co-creation of the storyboards for filming enabled pwNC and their care workers to collaborate reflectively to explore key aspects of their life that benefit from support, and consider how they would like this represented. Due to Covid, initial filming was a combination of self-filming and online video interviews, but this had limited engagement. As Covid restrictions eased in summer 2021, some in-person filming took place to supplement footage already created.

One participant had previously filmed with their PA, with the intention of showing future PAs their preferences about support as a person with cerebral palsy. Permission was given to utilise this footage, and it has been edited with remote interview and in-person footage. This offers an alternative to videos observed in other e-learning resources that rely on presenters, actors and scripted scenarios.

Co-design cycle 2 has seen the exploration of more potential approaches, to support learners to reflect on the content in relation to their own role and practice.

Reflective questions for viewers are being explored, with a view to developing “quiz” sections where learners and their training managers can track progress and review learning. This will help care organisations evidence learning for Care Quality Commission inspections, and give learners evidence for career progression. Some videos have been created with alternative audio tracks, with reflections from the video’s subject adding a new layer of learning. This can be seen in attached media files 1 and 2, “Going shopping – Emily negotiates the supermarket” and “Emily’s reflections on her supermarket trip”.

4.3.4. Technology

The design of NCKH is mobile-first, supporting on-the-go learning from mobiles or tablets. The learning platform offers various routes for learners to engage with content. These work independently, but also encourage flow between each mode of learning.

- *User Search* – searching for specific solutions to address immediate care issues or queries
- *User Browse* – browsing across via keywords or themes to develop their knowledge base
- *Collaborative* – supporting team learning with customisable and commentable lists

This pilot has enabled a testing ground for key concepts with collaborators and potential learners, and the anticipated next phase will further grow and embed these concepts. User search and user browse will enable individuals to save content into customisable personal “favourites” lists for revisiting. Team learning is supported by enabling colleagues to co-curate a “team library” of learning materials, relevant to current team needs. Team conversations and comments around the selected content supports shared learning and reflection. These elements are helping to build a foundation towards integrating artificial intelligence (AI) at the next phase of development, which will aim to support on the go learning with responsive “in the moment” searches.

4.3.5. Evaluation of the learning platform

The iterative evaluation is exploring different stakeholders’ perceptions around the potential of the learning platform to increase care workers confidence and knowledge when supporting pwNC. This has involved gathering feedback from care workers, clinical managers and training managers from different care settings to ascertain if they feel it is engaging and fit for purpose. PwNC and their families are offering feedback

on the representation of disabilities, different conditions and care relationships, to ensure these show best practice in supporting individuality and independence. Online questionnaires have included a combination of Likert scale questions, with a free text response for each to elicit more details. The free text has been analysed using a thematic analysis approach [17].

4.3.5.1. Cycle 1 evaluation. Online questionnaires were sent to 40 care workers who had not been involved in the design, as well the entire co-design group. This offered a broad range of perspectives across different care settings, and people with a diverse range of conditions. The questions walked them through the learning platform, asking questions as they engaged with different elements and content. **Table 7** summarises the key feedback themes that have informed content and technology development in co-design cycle 2. One of the key findings was the style of videos were different to other e-learning packages, and learners felt more engaged with the people featured. There was enthusiasm around how features such as the “team library” and learning assessment elements could help consolidate this approach to e-learning.

4.3.5.2. Cycle 2 evaluation. The proof of concept stage will conclude in mid 2022 with broader testing and evaluation of the resource and content developed. This will involve 60 care workers and managers across different care settings, who will assess relevance and suitability in their day-to-day roles. In addition, over 20 pwNC and their families will be invited to review NCKH for acceptability of representation of their needs. Again, this will offer a broad range of

Table 7. Themes from evaluation of co-design cycle 1.

What works well

- “Fly on the wall” style of films gives insight into why pwNC value independence
- Felt could get to know characters of the people filmed
- Showed subtleties of interactions between pwNC and care workers
- Challenges stereotypes around pwNC
- Felt unique approach to videos not seen on other e-learning platforms before
- Length of videos/audio working well at around 2 min
- Generally easy to navigate by browsing through themes
- Liked draft version of ‘team library’ function and mode of adding comments

What needs adding or improving

- Introductory films were felt to be needed to set out aim and approach of resource
- Desire for more assessment features which learners and managers can review
- Ensure that learning content fits audio or video well
- Positive response to alternative commentary idea on key videos
- Keen to see how the search function will evolve

perspectives across care settings and neurological conditions. Findings from this evaluation will help set the direction for the next stage of development by testing assumptions regarding user context, learning styles and behaviours, and inform the value proposition for learners (care workers) and customers (care organisations and pwNC) for scaling-up towards a nationally available resource.

5. Challenges

The Covid pandemic brought multiple challenges of its own, and exacerbated various pre-existing issues. Multiple evolving adaptations were needed to progress the project, plus empathetic patience for overstretched care workers and anxious pwNC who were shielding. Several of the project team are also clinicians and had to focus on frontline duties.

Changing to online co-design workshops and planning remote filming meant recruitment of pwNC and care workers could be national, not just regional. However, recruitment started around the start of the second Covid wave, reducing the number of people involved, and affecting ongoing engagement as infection rates worsened. It is also possible that Brexit impacted upon numbers of carers leaving the social care workforce. pwNC and their families felt anxious around this time, but also welcomed activity whilst shielding at home. Care home settings struggled to release care staff for ongoing co-design activity, so some continuity was lost. It was also difficult to recruit care workers for the evaluation of co-design cycle 1, delaying this stage. Co-design cycle 2 was also delayed during complex winter pressures, further delaying the final stage of evaluation. This evaluation is continuing into early summer 2022, to ensure adequate numbers of diverse respondents can be engaged during increasingly challenging times for health and social care.

Content creation was hindered, as not all participants took to self-filming, despite attempts at supporting skills development remotely. It is possible that skills sessions for new filmmakers may be more effectively delivered in person, with hands-on time with the equipment with guidance.

6. Future steps

The validation and proof of concept stages have enabled the production of a working pilot that offers a “blueprint” for our vision of a responsive approach to online social care learning, rich in documentary-led

multimedia content. The anticipated next stage of development of the digital technology and content will enable NCKH to scale up to serve a national audience, whilst providing a deeply personalisable learner experience.

The ambition for content development is to grow the bank of resources to comprehensively cover the symptom-led themes. A larger, more diverse group of pwNC and care workers will be sought for ongoing co-design, across conditions, ethnicity, social background and care settings.

The development of a robust artificial intelligence (AI) layer will significantly enhance the search capabilities of the platform. This will ensure searches offer highly relevant content, personalised to each learner, in a timely manner. In particular the AI will enable learners to type in an issue they are experiencing in their own words and the site will return recommendations to help answer “in the moment” queries.

Further market research around the pilot website will enable development of a flexible subscription model, offering affordable high quality online learning, and ensuring sustainability of the platform and its content strategy in the long-term. This will focus upon the needs of both employers within care settings and pwNC who are direct employers of their own personal assistants. Detailed ongoing evaluation of learner acceptance of the platform will be key to the growth and scaling up, and will feature formative and summative evaluations. Metrics will also be gathered around platform visitors and their journey. Features will be developed for learning managers and learners themselves to review learning engagement, and this data will feed into the evaluation.

7. Discussion

The NCKH project represents an evolution of the team’s interdisciplinary approach to developing flexible, co-designed, online education resources. Drawing upon skills from across clinical, research, digital technology and filmmaking practices, NCKH offers potential for multiple innovations to support learners in the social care sector. By testing “blueprints” of different approaches, iterative evaluation has rapidly fed back into the co-design process. Work done previously during myMND patient information project laid the foundation for NCKH’s co-design approach to developing documentary film-led digital learning resources, with a focus on a peer-to-peer ethos.

The co-design process helped bring insights into the complex challenges faced by pwNC and care

workers. NCKH offers learners the chance to learn from real life and relatable role models, as opposed to didactic presenter-led video favoured in traditional e-learning. The content focuses upon supporting independence holistically, rather than task-oriented care interactions. The social model of disability has informed content creation to challenge misconceptions that may contribute to the “neurophobia” that care workers may experience if unfamiliar with neurological conditions. The NCKH project has placed disabled people’s experiences at the forefront of the co-design process, which is central to the social model. It supports the principles of choice and control for pwNC in the care system, which is an important issue in the independent living movement.

Constructivist principles of education have underpinned the approach to platform navigation and content development, by presenting documentary-led video and audio in a flexible digital framework that promotes interaction and reflection. This can support learners to construct their own meanings, enabling them to meaningfully apply the new knowledge and insights within their care work practice. The future development of NCKH will maximise this, through AI supported searching, team learning features and motivating assessment approaches. Through the development of these features, NCKH is envisaged as ultimately offering adaptive learning, where the learning objectives, content, learning methods and pace of learning can be tailored to respond to individual learners’ ongoing, evolving education needs [18], working both in the moment for real-time queries, and as a go-to reliable source of insights into the world of neurological care.

Acknowledgements

The authors wish to acknowledge all of the care workers, people with neurological conditions and their families, colleagues, and stakeholders, who shared their time, views, ideas, and experiences in the project described. We would particularly like to thank those who appear in the videos and podcasts: Heather and Adam; Emily, Janet and Jess; Alison, Stephen, Laura and Amy; Sandra and Ruth; Judith and Gemma.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

The project has been funded by Neurocare (Sheffield Hospitals Charity), the University of Sheffield, Ufi VocTech Trust, and the National Institute for Health Research (NIHR) Sheffield Biomedical Research Centre (BRC). The research reported in this publication was supported by the National Institute for Health Research (NIHR) Devices for Dignity MedTech Co-operative. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

ORCID

Cathy Soreny  <http://orcid.org/0000-0002-6980-3982>
 Philippa Takhar  <http://orcid.org/0000-0001-6163-9041>
 Christopher McDermott  <http://orcid.org/0000-0002-1269-9053>

References

- [1] White S, Hobson E, Soreny C, et al. The development of the myTube website – a gastrostomy placement decision support resource. *CN Focus*. 2017;9(1):47–50.
- [2] The Neurological Alliance [Internet]. Neuro numbers 2019. A report by The Neurological Alliance; 2019. Available from: <https://www.neural.org.uk/assets/pdfs/neuro-numbers-2019.pdf>.
- [3] Medline Plus [Internet]. US National Library of Medicine; 2014 [cited 2021]. Available from: <https://medlineplus.gov/neurologicdiseases.html>.
- [4] The Neurological Alliance [Internet]. Neuro patience. Still waiting for improvements in treatment and care. The National Neurology Patient Experience Survey 2018/2019: technical report; 2019. Available from: <https://www.neural.org.uk/wp-content/uploads/2019/07/Neuro-Patience-Technical-Report.pdf>.
- [5] The Neurological Alliance & Thames Valley Strategic Clinical Network [Internet]. Transforming community neurology. What commissioners need to know. Part A – transformation guide; 2016. Available from: <https://www.neural.org.uk/publication/transforming-community-neurology/>.
- [6] Sue Ryder [Internet]. Time to get it right: a report on the provision of health and social care services for people with neurological conditions in England; 2019. Available from: <https://www.sueryder.org/sites/default/files/2019-02/Sue-Ryder-Time-To-Get-It-Right-report-2019.pdf>.
- [7] Skills for Care [Internet]. The size and structure of the adult social care sector and workforce in England; July 2021 [cited November 2021]. Available from: <https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/publications/national-information/The-size-and-structure-of-the-adult-social-care-sector-and-workforce-in-England.aspx>.
- [8] Skills for Care [Internet]. Recruitment and retention in adult social care: secrets of success Learning from employers what works well; May 2017. Available from: <https://www.skillsforcare.org.uk/Documents/Recruitment-and-retention/Secrets-of-success/Recruitment-and-retention-secrets-of-success-report.pdf>.
- [9] Lewis R, Kelly S, Cameron J, Sheffield Hallam University, et al. [Internet]. 2017. An Independent Analysis of the Care Homes Education & Training Evaluation (CHETE) carried out by the Community Practitioner Alliance (CIC); 2017. Available from: <https://www.shu.ac.uk/research/specialisms/health-and-social-care-research/reports/care-homes-education-and-training-evaluation>.
- [10] Hoppe HU, Joiner R, Milrad M, et al. Guest editorial: wireless and mobile technologies in education. *Journal of Computer Assisted Learning*. 2003;19(3): 255–259.
- [11] Social Care Institute for Excellence (SCIE) [Internet]. Creating an e-learning strategy for social care for England; 2004. Available from: <https://www.scie.org.uk/publications/consultation/elearningstrategy.asp>.
- [12] Disabled Peoples' International [Internet]. 1984 Disabled peoples' international leaflet – abstract from constitution; 1984. Available from: <https://tonybaldwinson.files.wordpress.com/2014/06/1984-dpi-disabled-peoples-international-leaflet.pdf>.
- [13] Mallett R, Runswick-Cole K. Approaching disability: critical issues and perspectives. London: Routledge; 2014.
- [14] The Higher Education Academy [Internet]. Biggs, J. Aligning teaching for constructing learning; 2005. Available from: <https://www.advance-he.ac.uk/knowledge-hub/aligning-teaching-constructing-learning>.
- [15] Palmer V, Weavell W, Callander R, et al. The participatory zeitgeist: an explanatory theoretical model of change in an era of coproduction and codesign in healthcare improvement. *Med Humanit*. 2019;45(3): 247–257.
- [16] Learning Light. E-learning and neurocare: a market analysis for neurocare knowhow (unpublished report). Learning Light Consultancy, Sheffield; 2020.
- [17] Braun V, Clarke V. Thematic analysis: a practical guide. London: Sage; 2022.
- [18] Kerr P. Adaptive learning. *ELTJ*. 2016;70(1):88–93.