

Research Article

Developing Social-ABI-lity: An Online Course to Support Safe Use of Social Media for Connection After Acquired Brain Injury

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ABSTRACT

Purpose: People who have an acquired brain injury (ABI) experience challenges using social media. Inversely, rehabilitation clinicians report feeling inadequately prepared to support them in its use. We aimed to develop a collaboratively designed, evidence-based online training resource to support people with an ABI to learn about using social media. Key recommendations for course design have previously been identified through a mixed methods approach, including (a) qualitative exploration of the experiences of people who use social media after ABI, (b) a scoping review to identify key features and effective teaching approaches from existing social media skills training programs.

Method: Further design recommendations were obtained in this mixed methods study through (c) collaborative design of course content and features with 23 people, including people with living experience of ABI and other key stake-holders, and (d) a pilot trial of the course prototype with four participants who had an ABI (two men, two women; aged 28–69 years).

Results: Training needs to be interactive, including practical components addressing online safety and wellbeing, and to explain how to use social media platforms to connect with others. The first social-ABI-lity prototype incorporated these findings. Pilot data indicated that the prototype was beneficial, with participants demonstrating small increases in social media confidence and knowledge. Areas for further refinement were also identified.

Conclusion: The social-ABI-lity self-directed online course is the first of its kind to support people with an ABI in using social media and will be a valuable resource for rehabilitation clinicians internationally. This resource may drive sustainable changes in participation by helping people with ABI to build their social media mastery and to participate in supportive online networks.

Correspondence to Melissa Brunner: melissa.brunner@sydney.edu.au. Melissa Brunner and Rachael Rietdijk indicate co-first authorship. **Publisher Note:** This article is part of the Special Issue: Select Papers From the Third International Cognitive-Communication Disorders Conference. *Disclosure:* This Social Brain Toolkit project represents a collaboration between The University of Sydney, University of Technology Sydney, Brain Injury Australia, and Changineers. The project was funded to be conducted from November 2019 to May 2022 through Insurance and Care NSW (icare), which included funding for Rachael Rietdijk's salary as Project Manager. The other authors have declared that no competing financial or nonfinancial interests existed at the time of publication. The Internet and social media have been used increasingly for work, education, and to connect socially, particularly during the coronavirus (COVID-19) pandemic (We Are Social, 2020). While using social media offers a great number of opportunities for connection, it also presents some safety risks (Gould et al., 2021), particularly for those with a cognitive-communication disability (Brunner, Hemsley, et al., 2021). People with a traumatic brain injury (TBI) have reported experiencing challenges in using social media (Brunner et al., 2020; Brunner, Palmer, Togher, & Hemsley, 2019), and rehabilitation professionals have described being inadequately prepared to support them in its use (Brunner, Hemsley, et al., 2021). As yet, clinical

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acquired brain injury (ABI) rehabilitation guidelines (e.g., Defense Health Agency, 2019; Togher et al., 2014) do not provide guidance on supporting people with cognitivecommunication difficulties to navigate the complexity of social media platforms safely, such as avoiding or responding to being "trolled" or "scammed."

As defined by the College of Audiologists and Speech-Language Pathologists of Ontario (CASLPO), cognitive-communication disorders are:

A set of communication features that result from underlying deficits in cognition. Communication difficulties can include issues with hearing, listening, understanding, speaking, reading, writing, conversational interaction, and social communication. These disorders may occur as a result of underlying deficits with cognition, that is, attention, orientation, memory, organization, information processing, reasoning, problem solving, executive functions, or self-regulation. (CASLPO, 2015, p. 2)

Acquired cognitive-communication disorders can occur due to a range of ABI diagnoses including progressive neurological disorders such a dementia or Parkinson's disease; nonprogressive neurological disorders such as stroke, TBI, or brain tumor; and other nonprogressive disorders such as depression or posttraumatic stress disorder (CASLPO, 2015). In particular, cognitive-communication disability following TBI can be diverse and long-lasting, and primary language impairments such as aphasia can also co-occur (Togher et al., 2014). As friendship and relationships are negotiated through the use of communication (Eckert, 2000), the changes in cognitive-communication that are typically experienced after a TBI often lead to social isolation, with the relationships that remain often being strained (Douglas, 2017). This isolation can have devastating effects on the individual after their injury and indeed disrupt the community around them, with a large proportion of people who have sustained a moderate-severe TBI experiencing homelessness and/or negative encounters with the justice system (Meulenbroek & Keegan, 2021).

To prevent these negative consequences, there is an urgent need for appropriate, evidence-based rehabilitation interventions to support people with cognitivecommunication disorders. These interventions should target reintegration into the community through building skills to have more successful communicative interactions. For communication to be effective and enjoyable, collaboration is required (Togher, 2013; Ylvisaker et al., 2005), which is why training for communication partners has become a central component of communication interventions with individuals who have cognitivecommunication difficulties following TBI (Wiseman-Hakes et al., 2020). The use of social media for connection and communicative rehabilitation has been identified as a realworld communication environment with potential to reduce social isolation for people with a brain injury through supporting their online interactions and raising awareness of cognitive-communication disorders (Brunner, 2020).

Brunner, Hemsley, et al. (2021) highlighted a need for evidence-based guidance for developing social media communication skills in clinical practice, and identified the requirement for interactive social media skills training that is co-designed, safe, and incorporates practical components to support people with brain injury (Brunner, Rietdijk, & Togher, 2022). However, in a search of online resources, no social media training tools were identified that were accessible or suitable for people with a brain injury (Brunner, Rietdijk, & Togher, 2022). As such, the aim of this research was to develop an evidence-based resource for people with an ABI to learn about using social media safely and meaningfully after their injury through an iterative cycle of collaboration with key stakeholders. Our research hypotheses were that (a) the online learning module would be acceptable and engaging for people with ABI and their communication partners, (b) participants would find the learning module functional and accessible, and (c) participants who completed the learning module would have improved levels of confidence in using social media and would participate in social media interactions more frequently.

Method

An online self-guided course, social-ABI-lity, was developed for people with ABI to learn skills in using social media safely and meaningfully. Using a mixed methods design (see Figure 1), the course was developed through incorporating findings from (a) the recommendations arising from a qualitative metasynthesis of a mixed methods program of research exploring the experiences of people with a traumatic brain injury (TBI) and their rehabilitation clinicians in using social media after their injury (Brunner, Hemsley, et al., 2021), (b) the results of a scoping review to identify key features and effective teaching approaches from existing social media skills training programs (Brunner, Rietdijk, & Togher, 2022), (c) designing course content and features through a cycle of consultation with people with lived experience of ABI and other key stakeholders, and (d) conducting a pilot study with four participants who have an ABI. Findings of the qualitative metasynthesis and scoping review have previously been reported. The present article traces the development of social-ABI-lity, which was informed by previous research and the collaborative design phase and pilot study reported in detail in this article.





Qualitative Metasynthesis of Social Media Use After TBI

Author MB's multilevel mixed methods doctoral research culminated in a qualitative metasynthesis (Brunner, Hemsley, et al., 2021) across three key levels of the sociotechnical system of social media use (i.e., social media, people with TBI, and TBI rehabilitation pathways) inclusive of (a) systematic reviews of the literature regarding the use of communication technologies and social media after TBI (Brunner et al., 2015; Brunner et al., 2017), (b) Twitter data and network analysis (Brunner et al., 2018; Brunner, Palmer, Togher, Dann, et al., 2019), (c) interviews with people with TBI (n = 13; Brunner et al., 2020; Brunner, Palmer, Togher, & Hemsley, 2019), (d) focus groups with TBI rehabilitation professionals (n = 11; Brunner, Togher, et al., 2021), and (e) a review of current guidance on safe use of social media (eSafety Commissioner, 2019a, 2019b). Five concepts that influenced social media use were identified and an evidence-based protocol was developed with suggested facilitators that can be used to address social media use during TBI rehabilitation and practical strategies on how to do so (Brunner, Hemsley, et al., 2021). Key recommendations from the metasynthesis were considered in the initial planning stage for the development of social-ABI-lity.

Scoping Review of Social Media Resources for People With ABI

To inform the next stage of development of social-ABI-lity, an integrative scoping review was conducted, with the methods and results documented previously (Brunner, Rietdijk, & Togher, 2022). The aim of the review was to identify social media skills training that could guide both people with ABI and their rehabilitation teams to build their skills in using social media safely and enjoyably. As such, the scoping review was used to locate and synthesize research investigating training for developing social media skills and safety, free online resources for social media skills training for the general public, and online support groups for people with ABI. The data collected were charted, critically appraised, and integrated qualitatively to identify key features of available social media training resources. In total, 47 peer-reviewed academic articles and 48 social media training websites were included, and 120 online support groups were identified. There were no suitable resources identified for social media skills training for people with ABI, with existing resources not addressing the specific challenges people with ABI are likely to encounter when using social media, and not meeting accessibility standards. This finding reinforced the need for the development of social-ABI-lity. The scoping review also raised further considerations for the planning of the content and format of social-ABI-lity, such as a focus on cybersafety in the content, an accessible, interactive, and practical format, and the need for user-centered design and evaluation in its development.

The Social Brain Toolkit

The development of social-ABI-lity is part of a larger body of work called the Social Brain Toolkit, which was conducted by the ABI Communication Lab at The University of Sydney. The Social Brain Toolkit comprises three online education and training resources that aim to support people with ABI to have positive interactions, whether in person or in online environments. The authors of this article, who include speech pathologists and other allied health clinicians, researchers, rehabilitation funders, and people with living experience of ABI, formed the project team and steering committee. The project team met monthly throughout the project period to review the findings arising from the research and make decisions on how to progress the development of the three online resources. Further guiding the development of the resources was the Social Brain Toolkit advisory committee, which included a person with an ABI, his family member, a speech pathologist working in a regional brain injury rehabilitation service, a speech pathologist working in private practice, a representative from the NSW Brain Injury Rehabilitation Program, and a representative from eHealth NSW. The advisory committee met via videoconference on six occasions during the project period to provide input on the research and development activities. Ethical approval to conduct these two studies was sought and received from the Western Sydney Local Health District Human Research Ethics Committee (6294 – HREA 2019/ETH13510).

In all stages of the planning and development of the Social Brain Toolkit, the project team has sought out information about the experiences and perspectives of a range of stakeholders to inform decisions about the content and format of the planned online resources. We have integrated principles of co-design in the collaborative design and pilot phases of the research program, through bringing the values of openness, respect, empathy, and collaboration to working with people with ABI, family members, clinicians, and other stakeholders (Agency for Clinical Innovation, 2019). Given the phased and iterative nature of planning and developing the Social Brain Toolkit resources, it has been relevant to engage with a range of individuals in different ways and at different timepoints to inform the next steps in development. The project team has used the Involvement Matrix (Smits et al., 2020), which is a tool for discussing roles of individuals in different phases of the project. Based on this tool, the project team and steering committee have played the role of decision-makers throughout the project, while being guided by the advisory committee, and research participant "co-thinkers" from earlier work and as part of the current project. The nature of the participants' role in the research reported in this article is best described as "collaborators," in that participants made recommendations and influenced decisions in the development of the social-ABI-lity resource (International Association for Public Participation, 2021).

Collaborative Design Phase

The collaborative design phase involved a sequence of two rounds of participant interviews: firstly about the topic of social media use after brain injury and resources needed, and secondly to provide feedback on a preliminary design of social-ABI-lity. The same participants completed both the first and second interviews. Participants who were participating outside of their paid work role (i.e., people with a brain injury and unpaid carers) were provided with a \$25 shopping voucher per 1-hr interview.

Recruitment

Recruitment of participants occurred via recruitment posts sent on social media (Twitter and Facebook) and through speech pathology and brain injury rehabilitation e-mail networks of the researchers. Recruitment information was also disseminated at one Australian metropolitan brain injury service (de-identified: Brain Injury Unit). All potential participants with ABI who expressed an interest in the study met with either authors P.A. or R.R. via Zoom (Zoom Video Communications Inc, 2021) to ensure they met study criteria, discuss the study, and ask any questions. Participants then completed an "Assessment of Capacity to Consent" process developed for this study (Jeste et al., 2007). All participants provided written consent before participating in the research.

Inclusion Criteria

All participants were required to be over 18 years of age. The inclusion criteria for specific participant types were as follows. Participants with ABI were eligible to participate if they:

- had a definite moderate-severe TBI at least 6 months previously based on the Mayo classification scheme (Malec et al., 2007; at least one of the following: loss of consciousness > 30 min, posttraumatic amnesia > 24 hr, worst Glasgow Coma Scale total score in the first 24 hr < 13, or evidence of a significant brain imaging abnormality). People with a nontraumatic brain injury were also eligible to participate (restricted specifically to the etiologies of stroke, hypoxic injury, brain tumor, poisoning, and infection);
- 2. were discharged or partially discharged from hospital, and able to spend time at home on a regular basis;
- had significant social communication skills deficits (either self-identified or identified by a usual communication partner);
- 4. had insight into their social communication skills deficits, as determined by P.A. or R.R. during the initial screening interview;
- 5. had adequate English proficiency for completing assessment tasks without the aid of an interpreter; and
- 6. had functional reading skills in English.

Exclusion criteria were:

- 1. aphasia of a severity that prevented any participation in conversation;
- 2. severe amnesia that prevented participants from providing informed consent;
- 3. dysarthria of a severity that significantly reduced intelligibility during conversation, as evaluated by the researcher;
- 4. drug or alcohol addiction that prevented participants from reliably participating in sessions;
- 5. active psychosis; and
- 6. co-occurring degenerative neurological disorder, more than one episode of moderate–severe brain injury or premorbid intellectual disability.

Family members were eligible to participate if they:

1. regularly interacted (i.e., at least once a week) with a person with ABI who was at least 6 months postinjury,

- 2. had known the person with ABI for at least 3 months, and
- 3. had not sustained a severe ABI.

Professional or student professionals were eligible to participate if they were currently employed in a role (or studying toward future employment in a role) that would involve interacting with people with ABI. Speech pathologists were eligible to participate if they were employed in a clinical speech pathology role working with people with ABI for at least 2 years or equivalent.

Process

Participants were interviewed via Zoom on two occasions, while at home or in a private location in their workplace. The initial interview was completed by authors P.A. or R.R. between June and December 2020, and the follow-up interview was completed by author P.A. between November 2020 and February 2021. The initial interview incorporated completion of demographic questionnaires for all participants, a cognitive-communication assessment for participants with ABI, and an interview about needs for communication resources after ABI, which was supported using an interview guide. The cognitive-communication assessment included the Glasgow Outcome Scale Extended (Teasdale et al., 1998), Care and Needs Scale (Tate, 2004), Functional Assessment of Verbal Reasoning and Executive Strategies (MacDonald, 2005; Task 4 only), and the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS; Randolph, 2012). A range of topics were covered in the interview, but this article will focus on the content of the interview that was relevant to the development of social-ABI-lity. The interview guide on this topic was developed for the purpose of this study and is provided in the Appendix. The presentation of questions was supported via presentation slides with written questions and images to support comprehension, displayed to participants using screensharing. The initial interview was scheduled across two appointments for participants with ABI to reduce the impact of fatigue. Both P.A. and R.R. are female speech-language pathologists with experience working with people with a brain injury and their family members. The interviewees were not known to the researchers prior to the study. Interviewees were informed that the research team were conducting the interviews to support the development of online resources for communication after brain injury.

Following these initial interviews, participants' priorities were incorporated into preliminary designs for the Social Brain Toolkit resources and represented to them in the follow-up second interview for further guidance and feedback prior to continuing and refining the design development and content build. This article will focus on feedback from these interviews that was relevant to the social-ABI-lity resource. Participants were able to

view the course layout, structure, and example content for social-ABI-lity via screensharing of an initial build using the Thinkific web platform (Thinkific Labs Inc, 2021). The interviewer asked participants to guide her to navigate the website, while encouraging them to share their thoughts and impressions. The follow-up interview guide is provided in the Appendix.

Pilot Study Phase

Based on feedback during the collaborative design phase, the preliminary design of the social-ABI-lity resource was further refined using the Thinkific web platform and then tested in a pilot phase. Each participant was offered a \$50 shopping voucher after the initial assessment, and a \$50 shopping voucher after the follow-up interview as a reimbursement for their time.

Recruitment

Recruitment occurred via the same sources and using the same procedure as the collaborative design phase, as described above. The inclusion criteria followed were also the same as for participants with ABI in the collaborative design phase, and participants involved in the collaborative design were also able to take part in the pilot study. Only participants with ABI were involved in the pilot study.

Process

Each participant attended an initial assessment via Zoom with authors R.R. or P.A. to complete demographic questionnaires, a communication assessment, and a questionnaire about social media use. Participants were located at home for this assessment. Following their assessment, each participant was provided with log-in details and guidance to access the social-ABI-lity course. They were asked to complete the course over a 1-month period. The participants worked through the course independently and were provided with opportunities to contribute their feedback throughout the course. If participants had not completed the course after 1 month, the participants received a reminder. Within 1-2 weeks following completion of the course, the participants were interviewed while at home via telephone or Zoom by author M.B. to again complete the questionnaire about social media use, and discuss their overall impressions of the course and any suggestions for improvement. M.B. is a female speech-language pathologist and researcher with experience working with people with a brain injury, who had not met the interviewees prior to the interview. Interviewees were informed that M.B. was interested in discussing their feedback on social-ABI-lity to support further improvements to the resource.

The interview guide was developed for this study and is reported in the Appendix. Initial assessments were completed from December 2020 to March 2021, and follow-up interviews were completed from February to May 2021.

Data Collection

Participant interviews were recorded and transcribed verbatim, and interviewers made field notes during the interview. Transcripts were not provided to participants. For the first interview in the collaborative design phase, participants were provided with a summary of their interview and invited to clarify or add further points. Data to describe the characteristics of participants were also gathered from the following sources:

- Participant with ABI Demographics form (for participants with ABI in both collaborative design and pilot studies): posttraumatic amnesia duration (Tate, 2004), months post-injury, gender, age, and frequency of Internet usage
- Communication Partner Demographics form (for everyday communication partners in collaborative design phase): age, gender, and frequency of Internet usage
- Speech Pathologist Demographics form (for professionals in collaborative design phase): age, gender, and years of experience working with people with TBI
- Professional Demographics form (for professionals in collaborative design phase): age, gender, and occupation
- Sydney Psychosocial Reintegration Scale (Tate et al., 2011) and Glasgow Outcome Scale Extended (Teasdale et al., 1998; for participants with ABI in collaborative design and pilot phases)
- Functional Assessment of Verbal Reasoning and Executive Strategies (Task 4 only; MacDonald, 2005). This assessment was administered via Zoom with participants with ABI in the collaborative design phase only with permission via a letter of no objection from CCD Publishing.
- Repeatable Battery for the Assessment of Neuropsychological Status (RBANS; Randolph, 2012). This assessment was administered via Zoom with participants with ABI in the pilot study with permission via a letter of no objection from Pearson Clinical Assessment.

For participants in the pilot study, outcomes related to social media use were evaluated using an ABI Social Media Questionnaire (available on request from the authors), administered at a pretest during initial assessment and as a posttest at the follow-up interview. Questionnaire items included number of social media accounts, size of individual's network, frequency of use, categories of postings, ratings of confidence in using social media (using a 5-point Likert scale of *not at all* to *extremely* confident), and response to questions about a hypothetical romance cyberscam and knowledge of hashtag use.

Data Analysis

Interviews during the collaborative design phase and feedback interviews with pilot study participants were transcribed and analyzed using conventional content analysis (Hsieh & Shannon, 2005). This involved deriving codes from reading and rereading of interview transcripts and then organizing related codes into categories. Example quotes relevant to each category were identified from the transcripts. This process was completed by M.B. and R.R., who are both qualified speech pathologists and researchers with experience in qualitative analysis. Coding was supported using NVivo software. Participants were not involved in reviewing the data analysis. In order to strengthen the trustworthiness of this qualitative content analysis (Kyngäs et al., 2020), discussions between M.B. and R.R. were used to explore and refine the categories and groupings of meaning, and direct and paraphrased quotes were incorporated throughout the reporting of results to contextualize and situate our interpretations.

Analysis of data also involved descriptive summaries of the demographic variables and assessment scores of participants. Given the small sample size, ratings of confidence, and knowledge at pretraining, posttraining, and follow-up, as well as ratings of the module's usefulness and the likelihood of recommending the course to others were also analyzed descriptively. Guidelines for reporting qualitative research (Tong et al., 2007) and pilot studies (Thabane et al., 2010) were used.

Results

Collaborative Design Phase

Participants

A total of 23 people were recruited for the collaborative design phase, which included people with an ABI (n = 5), everyday communication partners (n = 4; a daughter, a partner, a sister, and a daughter-in-law), speechlanguage pathologists (n = 4), and other health care professionals (n = 10; five support workers, a physiotherapist, occupational therapist, psychologist, client services manager, and a student speech-language pathologist). All participants with ABI were male, had severe injuries (range of posttraumatic amnesia duration = 14–123 days) and were several years postinjury (range: 1.5–15 years). Participants with ABI ranged in age from 32 to 63 years. All participants had limitations in areas of psychosocial functioning as evaluated using the Sydney Psychosocial Rating Scale, with ratings on the Glasgow Outcome Scale Extended ranging from low moderate disability (n = 3) to upper moderate disability (n = 2). All participants had impairments in cognitive-communication skills, with scores falling below cutoff on the Functional Assessment of Verbal Reasoning and Executive Strategies. All participants with ABI used social media daily. Everyday communication partners (age range: 29–54 years) were all women, and all were daily Internet users. Speech-language pathologists (age range: 30–54 years) were all women, with experience working in ABI ranging from 6 to 20 years. Other health care professionals (age range: 20–65 years) were eight women and two men, with experience working in ABI ranging from 0 to 50 years.

Interviews

The sections of initial interviews related to social media use after ABI ranged from 2:47 to 18:12 min (M = 11:25), with 19 of these initial interviews relevant to this study. A total of 22 participants completed follow-up interviews and provided feedback on the social-ABI-lity preliminary design, with this section of the interview ranging from 8:39 to 26:06 min (M = 16:07). One participant (an everyday communication partner) was unable to be contacted to complete the follow-up interview.

Content Analysis

There were six categories identified in the first interviews with participants (see Table 1). These categories guided the development of the preliminary design for social-ABI-lity.

In the follow-up interviews with participants to seek feedback on the preliminary design of social-ABI-lity, the two categories identified were (a) aspects endorsed and (b) suggestions for improvements (see Table 2).

Course Prototype Development

Findings from the collaborative design phase was integrated with knowledge gained from the prior research stages. Key recommendations for course design were identified in the scoping review (Brunner, Rietdijk, & Togher, 2022), specifically that the training was to be interactive and include practical components addressing online safety and wellbeing, and how to use social media platforms to connect with others. The initial priorities identified by the participants in the collaborative design phase (as detailed above) were the need to clearly incorporate elements of cybersafety throughout the course and to make the course as accessible as possible for people with a brain injury. The first prototype outline of the social-ABI-lity course incorporated these findings, along with priorities for learning identified in previous research (Brunner, Hemsley, et al., 2021) and guidance provided

Table 1. Categories and codes identified in initial collaborative design interviews.

Category	Codes
Context of social media in society	Social media is challenging for everyone
"People do risky things on social media everywhere all the time, and that's fine, that's life." (P6, client services manager)	Increased use of social media during COVID-19 restrictions
Personal factors	Preinjury use of social media
"I really like following other friends I like to make comments to those people.	Postinjury changes in using social media
I probably do that more often now than I did before." (P17, person with an ABI)	Preference for different platforms
	Personal preferences for communication
The risks in communicating online	Risks of cyber-scams
"It can potentially be challenging because of those difficulties around self-regulation	Risks to reputation
The herefite of connection	Communication challenges
"It can be a really good way to reconnect with pre-injury friends and family it can	Peer support from others with ABI
give a sense of still feeling engaged and keeping up with what's happening in	Connection with the wider world
their social world, but the broader world as well." (P5, speech pathologist)	
The role of other people	Support as part of rehabilitation
"I actually said to him, at the moment we don't want too many platforms for him,	Support from family, friends and paid workers
and his OT is slowly introducing apps I'll always talk it over with his sisters or	
you know, his stepmum or his best mate." (P22, communication partner)	
Navigating social media successfully	Skills for connection
"I m usually pretty conservative when it comes to what I post, yen so I don't get troils	Strategies for safety
and think about it first before doing anything" (P4 person with brain injury)	

Note. ABI = acquired brain injury.

by the Social Brain Toolkit project advisory committee (see Table 3).

The social-ABI-lity prototype was designed to be a self-directed online learning course for people with an ABI, and their supporters, to learn about the basics of using social media and how to stay safe online. The intent of the resource was to provide people with an ABI with knowledge and skills to reduce the risks of online interaction, while also accessing the benefits of social connection and support that can occur in social media platforms. Collaborative design participants provided feedback on the initial design and prototype and were forthcoming with ideas and constructive advice on how to make the prototype as comprehensive as possible, while remaining accessible, easily understood, and relevant for people with an ABI. They identified areas where better use of white space and formatting of font could improve access, suggested providing a printout to support memory, and gave detailed commentary about which content topics they thought worked well or if there needed to be some additions or alterations. Overall, their feedback highlighted the potential benefits of people with an ABI and their supporters in having access to a course like this due to its relevance in today's society and its basis in real-life activities.

Throughout and following the collaborative design process, the prototype of the course was built using a free account in the platform Thinkific. The prototype addressed priorities for content, accessibility, and cognitivecommunication strategies to support the needs of people with ABI as identified in the collaborative design process and the scoping review. The prototype course included four modules: (a) What is social media? (b) Staying safe in social

Table 2. Categories and codes identified in follow-up collaborative design interviews.

Categories	Codes
Aspects endorsed	Relevance of content
	Applicability to people with brain injury and support networks
Suggestions for improvements	Reduce quantity of text
	Improve visual aspects: Color contrasts, use of images
	Define the target audience
	Provide more practical demonstrations or examples
	Expand information on safety and privacy
	Improve navigation instructions
	Increase clarity of language
	Develop translations/other versions for international use Provide links to brain injury groups and mental health services

#TwitterMind research (Brunner, Hemsley, et al., 2021)	 Being safe online Knowing the basics of how to use social media Knowing who to connect with Mixed learning approaches are useful, for example, a blend of written, visual, multimedia, and interactive resources
Scoping review (Brunner, Rietdijk, & Togher, 2022)	Interactive training with practical components
	 Cover topics of: online safety, the basics of how to use platforms, how to connect with others, having a social media buddy/support group
Collaborative design participants	Allow for personal differences
	 Educate about risks and safety
	 Teach operational use/strategies
	 Build in support from family, friends, or clinicians
	 Address issues of accessibility
The Social Brain Toolkit project advisory committee	Being safe online is very important
	 Need to consider different levels of social media skill
	 Need to consider different levels of awareness and cognition
	 Potential to incorporate training suitable for health professionals, family, and friends

Table 3. Priorities for learning identified from multiple sources incorporated into the development of the social-ABI-lity course.

media? (c) How do I use social media? and (d) Who can I connect with in social media? In these modules, there was a combination of simple written information, videos, and questions for people with ABI to complete in order to accommodate difficulties in attending to written information and to provide interactive elements to engage and maintain attention throughout a self-directed course. To support memory, there was also a printable worksheet for people to write down responses to reflective questions and keep the key messages of the four modules, for potential sharing with a support person or clinician in the future. During the content build of the prototype, all written information and scripts for the videos were reviewed for accessibility using Microsoft Word's readability statistics (with the aim of all content to be no greater than sixth-grade reading level). All included pictures were given an alt text description, and the text font size was enlarged where possible.

Pilot Study Phase

Participants

Five participants were recruited to the pilot study, with one participant withdrawing prior to completing the initial assessment due to limited time in his schedule to participate. One participant involved in the collaborative design phase also participated in the pilot study. Participants' demographic information and scores on the psychosocial and cognitive assessments are reported in Table 4 (pseudonyms are used throughout to protect participant confidentiality). Three of the participants had sustained a TBI, and one participant had experienced a hemorrhagic stroke. The participants' functional outcomes ranged from upper severe disability to lower good recovery, based on the Glasgow Outcome Scale Extended. All participants demonstrated impairments in cognitive functioning on at least one domain of the Repeatable Battery for the Assessment of Neuropsychological Status.

Participant Outcomes

Pilot study data indicated that the course may be of benefit, with participants' pretest and posttest data on social media use, confidence, and knowledge reported in Table 5. No large changes were observed in the participants' friends or followers counts, nor major changes in the frequency of their posts or interactions. However, Ash, Sam, and Toni all reported they had increased awareness of their activity and interactions in their preferred social media platforms and had consciously altered how often they commented (Ash) or reduced the number of accounts they followed/friended (Sam and Toni). In terms of confidence, two participants reported small increases in confidence, one participant maintained their confidence level, and one participant felt less confident after completing the course. One participant showed an increase in their knowledge of potential markers of a romance cyberscam, and all participants gave more specific advice to the hypothetical friend who was being scammed. For example, at pretest, Jessie advised their friend to "Run! Stay away," whereas at posttest, they advised "Don't give your personal details, like your address." Three participants demonstrated an increase in their knowledge of hashtags, with two participants who were previously unsure about hashtags being able to generate relevant hashtag suggestions in response to a brain injury fundraising event case scenario at posttest, for example, at pretest Sam stated, "I'm not sure" and at posttest provided the hashtag suggestion #BrainInjuryAwareness.

Content Analysis

The duration of the feedback interviews with participants ranged from 18:32 to 1:00:58 min. The two categories

Table 4. Participant demographics and scores on psychosocial and cognitive assessments.

Participant pseudonym	Ash	Jessie	Sam	Toni
Age	61	45	28	69
Gender	Male	Male	Female	Female
Years of education	13	15	12	16
Vision impairment	No	No	Double vision	No
Hearing impairment	No	No	No	No
Type of ABI	Hemorrhagic stroke	TBI	TBI	TBI
PTA duration	Not applicable	Not available (7 months inpatient rehabilitation)	60 days (self-reported)	Not available (TBI not diagnosed at time of injury)
Time postinjury	6.5 years	40 months	29 months	21 years
Frequency of Internet use	Every day	Every day	Every day	Every day
GOSE	Lower good recovery	Upper moderate disability	Upper severe disability	Upper moderate disability
FAVRES	DNC	2	DNC	2
Accuracy	D NO	2	DNIG	2
FAVRES	DNC	0	DNC	3
Rationale		10	-	2
SPRS Work and Leisure	14	10	/	6
SPRS Relationships	12	10	<u>/</u>	6
SPRS Living Skills	15	14	(14
SPRS Total	41	34	21	26
RBANS IS Immediate Memory	76	73	65	61
RBANS IS Visuospatial/ construction	89	105	69	109
RBANS IS Language	85	95	75	111
RBANS IS Attention	97	68	40	94
RBANS IS Delayed Memory	89	64	44	52
RBANS IS Total	83	76	51	81

Note. SPRS scores range from 0 to 16 for each domain and a total score between 0 and 48, with higher scores reflecting higher levels of functioning. All FAVRES scores are shown as raw scores (range: 0-5), with higher scores indicating more successful task completion. RBANS IS Total scores are shown as standard scores between 40 and 160 and are indicative of average/mild impairment (\geq 70), moderate impairment (55–69), and severe impairment (<54). ABI = acquired brain injury; TBI = traumatic brain injury; PTA = pure-tone average; GOSE = Glasgow Outcome Scale Extended; FAVRES = Functional Assessment of Verbal Reasoning and Executive Strategies; DNC = did not complete the task; SPRS = Sydney Psychosocial Reintegration Scale; RBANS = Repeatable Battery for the Assessment of Neuropsychological Status; IS = Index Score.

identified in the interview were Positive Outcomes and Course Feedback and Recommendations.

Positive outcomes. The participants discussed how what they learned in the course had changed their perceptions of how they could use social media and how they had put some of the safety considerations into practice. They shared what they felt had changed from working through the course, with Jessie noting they had built confidence in their own social media skills: "I didn't know I could do it." Toni felt less confident but reflected on how they had changed their social media habits:

I guess I realized how much time I spend on it...my communication is my biggest problem, and the one that impacts on me socially, so I tend to want to avoid it, and social media is a good way for me to avoid it. So I learnt to stay off it. (Toni)

For Sam, the course helped them realize different options and possibilities, particularly around their social media privacy settings, "I said 'oh I don't know this' doing this, so I paused, I go to my Facebook change it, and come back and doing the course." They reflected on how completing the course has helped them learn how to be safer online through tips on how to change their settings and being more aware of who they connect with in social media:

I want to become safe, I forgot which one is it, and I went to my Facebook setting and I changed so make it more secure...to unfriend also the people that I've never met. I used to have around 4,000 people, because I just add, add, add them, because another thing was like, especially after my brain injury, I used to accept anyone. (Sam)

All of the participants found the course beneficial, with some finding it validating to learn about the complexity and ephemeral nature of social media platforms, "There's a lot of options, which I did know, but it just confirmed it." (Jessie). Although they found the content valuable, one participant found the amount of information in the course challenging "I think it's a good thing, but I got lost in the details" (Ash). For these participants, the most significant outcome of completing the course was centered around their desire to "use my situation to Table 5. Participant data for pretest and posttest of social media use, confidence, and knowledge.

Participant pseudonym	Ash	Jessie	Sam	Toni	
Preferred platform/s	Facebook	Facebook	Facebook (and Instagram at posttest)	Twitter	
		Activity (preferred	l platform)		
Pretest	15 friends	429 friends	Approximately 900 friends, more than 2,000 people following their page	22 followers, following 448 accounts	
Posttest	15 friends	427 friends	1,050 friends with 2800 followers	22 followers, following 468 accounts	
	Frequency of social media use (preferred platform)				
Pretest	0 posts in past month, regularly liked other friends' posts, no comments made	1 post in past month, reacted multiple times every day to friends' posts, and commented 1/week on posts	Posted 5 times/day but some kept private with 2–3 visible to everyone, reacted to friends posts approxi- mately 5/day, did not comment on others posts, sent 5–6 direct messages/day	Sent retweets every day, liked tweets every day, sent 1–2 tweets/week (approximately 6/month), used mostly to follow journalists and keep up with news	
Posttest	Read posts but never posted, reacted/liked posts every day, commented often but not as often as they would like as there may be consequences of their comment (has more awareness of it), deliberately reconnected in the past month with friends from school and some work colleagues (Facebook was originally just used with ABI friends)	0 posts in last week (did not post a lot, mostly using messaging), often reacted to others posts, rarely commented, sent direct messages approximately 2/day	Sent 0 posts this week ("got sick of it"), sometimes reacted to others posts, commented "once in a while," sent 3 direct messages to family/friends and responded to them, changed profile picture and cover photo	No posts but sent self an email through Twitter, rarely liked any tweets, often retweeted, "stepped back a bit" since doing course and reduced number of people they followed	
	mondoj	Social media co	onfidence		
Pretest Posttest	Moderately confident Moderately confident	Moderately confident Very confident	Not at all confident Slightly confident	Moderately confident Not at all confident	
_		Knowledge of cy	berscams		
Pretest	4 correct, 1 incorrect	2correct, 0 incorrect	2correct, 0 incorrect	4correct, 1 incorrect	
Posttest	2 correct, 0 incorrect	3correct, 0 incorrect	1 correct, 0 incorrect	1 correct, 0 incorrect	
Protoct	1 correct 0 incorrect	1correct 0 incorrect	2 correct 0 incorrect	3 correct 1 incorrect	
Posttest	2 correct 0 incorrect	3 correct 2 incorrect	2 correct 0 incorrect	3/3 correct 0 incorrect	
1 0011001		Generation of h	ashtaas		
Pretest	"I'm not sure"	#BrainInjuryAwareness	"I'm not sure"	#BrainInjury	
Posttest	#TBI	#BrainInjury	#BrainInjuryAwareness	#ScrambledEggs	

Note. ABI = acquired brain injury; TBI = traumatic brain injury.

benefit others" (Jessie). They all wanted to "give back" to the ABI community and contribute to an endeavor that may support others with ABI in future, "doing the course for me, it was so good. Because I'm happy to help out, because sharing this what benefitted me it is benefit somebody else who has the same injury as me" (Sam).

Course feedback and recommendations. The participants valued the key components of the course, with the "premise of the course is a really good thing" (Ash) and felt that they benefitted from doing the course and that others with an ABI would as well, "I reckon to other people who had a brain injury like me, I really benefit so many things from it" (Sam). The participants also gave detailed commentary about which content topics they thought worked well or if there needed to be some additions or alterations, suggesting that "the really basic stuff, a person with ABI might use this every time [they go on social media]" (Ash). Similar to the collaborative design participants, the pilot participants identified areas where better use of white space and formatting of font could improve access, such as using a "bigger font size" (Ash), with short, clear sentences with key info in bold text, and short, simple instructions to follow. They suggested providing memory support strategies such as having more "printable resources that people can refer back to when using social media" (Ash) as there was "too much info for an ABI dude to remember" (Ash). Three participants preferred the videos as a means for learning content, whereas one participant reported that they found the videos the least helpful.

The participants spoke about their difficulties with memory and identified that being able to work through the course at their own pace was important, as "you get distracted. It's good to go back to it. Like it doesn't disappear" (Jessie). They felt this might facilitate engagement with the course and help to alleviate anxiety for some people with an ABI, stating it was "important to know that you can stop at any time, and your work can be saved, and you can restart where you left off" (Ash). Some considered that this course could be used a tool to support the balance between vulnerability and impulsivity that people with an ABI can experience:

You can sell it as something that makes people feel safe and protected, that would be good. Because I think it's really frightening to be brain injured, just because you're uncertain of everything that you do. And the other side of that is the impulsiveness where you're unafraid, you're not aware of the dangers. So, it's like a tightrope. (Toni)

All of the participants felt that having a support person to work through the course with would be beneficial, with Sam suggesting "it would be helpful if I had speech therapist with me, so that I can discuss and explore and talk to someone or something.... I don't recommend with carers. The best thing is with therapists or with a friend" (Sam). Toni felt that having someone to discuss the course, a support person to prompt them and help them, would likely help them to build their knowledge and skills over time:

I do think having somebody to support you doing it is the thing that helps you continue. And I mean, I just think you can't underestimate how important support is to someone with a brain injury to keep them on track, focused and giving them feedback and reinforcing it, talking about it when they're doing it so they can maybe ask a question. Because that's sometimes a very frustrating thing for everybody with computers, you want an answer, but you can't talk to the screen. (Toni)

Discussion

The two studies described in this article were prompted by previous work (Brunner, Hemsley, et al., 2021; Brunner, Rietdijk, & Togher, 2022) that demonstrated the need to develop an intervention addressing social media use after ABI. The collaborative design phase was built on this previous research to identify key content to prioritize in the social-ABI-lity online learning module. The feedback from the collaborative design participants on the initial design of the module indicated that content was relevant, features were valued, and the tool was applicable to people with ABI. The potential challenges identified in this first study guided further development of the social-ABI-lity prototype, before commencement of the pilot study.

Given the iterative process of collaborative design, our hypotheses for the subsequent pilot study phase were that (a) the learning module would be acceptable and engaging for people with ABI, and (b) participants would find the learning module functional and accessible.

Results from the qualitative analysis of interview data suggest our hypotheses were partially supported as participants reported that they found the course acceptable, engaging, functional, and accessible. However, they provided specific feedback that would improve these aspects for future iterations of the course. Our third hypothesis was that participants who completed the learning module would have improved levels of confidence in using social media and would participate in social media interactions more frequently. This hypothesis was also partially supported, with most participants reporting that their confidence in using social media had improved, yet they did not interact more frequently. Although their frequency of interactions did not increase, the way in which they interacted did change, with participants observing that they were more aware of how they interacted and with whom. Findings indicate that we may be able to train some aspects of social media communication skills for people with an ABI using an online, self-directed course.

The results also highlight the challenges of measuring the outcomes of a social media skills intervention. Although confidence was an important measure in this study, it should not necessarily be considered a reflection of the participants' competence or mastery in using social media. Indeed, performance ratings in individuals with or without brain injury can be susceptible to being overestimated (Kennedy & Coelho, 2005). Confidence has also been linked to mood, whereby people can underestimate their performance when lower in mood, and overestimate when experiencing higher mood (Bourke et al., 2022). While the reported increases in confidence for some participants are a positive outcome, this finding should be interpreted with caution. It is recommended that further research focusing on training in social media use to support social participation and engagement integrate measures of mood, alongside confidence. A further issue in evaluating the outcomes of this intervention is the lack of assessments relevant to evaluating competence in using social media. In this study, we trialed questions about social media knowledge (romance cyberscam and hashtag use), but there were not clear improvements in accuracy of participants' responses to these questions. To strengthen future research, there is a need for a valid, reliable assessment of social media skills relevant to people with ABI.

The results of the cognitive-communication assessments indicated that participants in the pilot study phase had impairments in skills such as memory and verbal reasoning. These impairments are common in the ABI population, and the prototype was, therefore, developed to accommodate to communication needs through features such as simple text, short videos, large font size, and printable memory aids. The pilot study demonstrated that while these accommodations were helpful, participants still found it challenging to learn and retain new information through this self-guided course. Participants provided feedback on specific accommodations that would assist further, such as additional white space, formatting of text to highlight key points, and simplification of content. This participant feedback has been integrated in the next iteration of the course.

While the self-directed nature of the course was acceptable to the participants, they discussed the importance of having a support person to work through the course with them, whether that be a clinician, a support worker, or a friend. This aligns with knowledge in the field of TBI that collaborative, contextualized rehabilitation approaches are more meaningful (Ylvisaker et al., 2002) and are recommended in TBI evidence-based practice guidelines and reviews (Meulenbroek et al., 2019; Togher et al., 2014), and that communication partners have a critical role in the communicative successes and breakdowns of people with TBI in everyday interactions (Gordon & Duff, 2016). Indeed, the social-ABI-lity course could be used as a tool to promote a Ylvisaker's contextualized rehabilitation approach where communication partners could work together to complete a meaningful goaldirected task, taking their time and discussing the process as they move through the course, and where knowledge and skills would be developed through teamwork, rather than through adopting a more traditional teacher-learner dynamic that provides a person with ABI with explicit instruction. Additionally, previous research evidence suggests that computerized or technology-based applications are likely to be more beneficial as a complement to intervention rather than being used in isolation (Meulenbroek et al., 2019). The pilot participants felt that it was important that a support person could be available to help people with a brain injury to stay focused, to provide them with feedback and reinforcement, and to provide the opportunity to discuss the content as they progress. It was discussed that having someone there who would be able to prompt them and help them would make completing the course much easier and likely be more beneficial for people with an ABI. As such, this self-directed course could be used as guidance for rehabilitation clinicians in helping people to navigate the issues that come with using social media.

Developing social-ABI-lity Beyond the Pilot Phase

Since the conclusion of the pilot study phase, the Social Brain Toolkit research team have conducted a pilot study investigating the use of private, moderated Facebook groups for people with ABI to improve skills in communicating online (Brunner, Rietdijk, Summers, et al., 2022). This study has been in in collaboration with Brain Injury Australia, where people with an ABI complete the social-ABI-lity prototype course and then join a closed Facebook group to practice their social media skills and communication for 3 months.

Subsequently, the course has been refined further and rebuilt on our Lab website using fit-for-purpose design and incorporating participants' feedback and suggestions for the content, accessibility, and modes of learning presented in the course. Additionally, several strategies to support the implementation of the course were coproduced with people with ABI, clinicians, and communication partners, including accessibility requirements, a value proposition on the website home page, and clearly communicated time estimates of each module and the course as a whole (Miao et al., 2022). social-ABI-lity was launched in January 2022 at the International Cognitive-Communication Disorders Conference 2022, and it is now available for free, accessible anywhere and anytime (de-identified; https://abi-communication-lab.sydney.edu.au/ courses/social-ABI-lity/). People with an ABI can progress through the course at their own pace, and they are able to track their progress as they work through the course and receive a certificate at the end. Now that the course has been made publicly available, a hybrid implementation-effectiveness phase of the social-ABI-lity online course research has begun. On entry to the course, participants consent to research data collection before being provided with access to the course. Implementation and effectiveness data about course participants will be collected for 6 months on entry, completion, and 3-month follow-up, as well as individual think-aloud study interviews with participants (Miao et al., 2021).

Limitations and Directions for Future Research

There are several limitations to this research. First, the collaborative design participants were asked about all three components of the Social Brain Toolkit during their interviews. Therefore, their feedback specific to social-ABIlity may have been affected by fatigue, reduced concentration, and timing restrictions. Second, the sample size of the pilot trial was is small given this was a proof-of-concept study. Third, self-reported measures of social media use were used in this study. Fourth, generalizability of these findings may also be limited by the fact that there was limited recruitment of women with ABI and male family members in the collaborative design phase. Additionally, given that participants selfselected into this intervention and their own level of motivation may have been higher than other people with an ABI. To make stronger conclusions about the effectiveness of this intervention, future researchers would need to test this intervention with a larger group of participants and to include validated measures of social media use that provide normative data, for example, the Community Integration Questionnaire-Revised (Callaway et al., 2016). A larger study would provide an opportunity to identify characteristics of participants with ABI, which influence outcomes of a self-directed program. It would also be of benefit to examine efficacy of the intervention using different modes of support, such as a social media support person or rehabilitation clinician, and against a control group. Finally, due to funding and time constraints, the involvement of people who have living experience of ABI and other key stakeholders in the ABI rehabilitation field in the development of social-ABI-lity is best described as a collaboration, rather than a co-design partnership (International Association for Public Participation, 2021). Future research needs to embrace the involvement of people with ABI as co-researchers from inception of the project design and throughout implementation, and to validate and support their inclusion and expert contributions to the research cognitively, emotionally, and financially based on the individual needs and wishes of each co-researcher with an ABI.

Conclusions

The social-ABI-lity self-directed online course is the first of its kind to support people with an ABI in using social media after their injury. This study was the first logical step in proof-of-concept and feasibility in examining the incorporation of targeted social media communication skills instruction for people with ABI. It provides initial evidence that this type of intervention can produce improvement in awareness and confidence in social media skills and use. Findings indicate that we may be able to train some aspects of social media communication skills for people with an ABI using an online, self-directed course. Additionally, the results indicate that such an intervention is perceived as acceptable and engaging. In this study, we provided an intervention template upon which future research can build, particularly with regard to efficacy as it is likely that this course would be most beneficial as a complement to intervention with a rehabilitation clinician, rather than as a standalone treatment. However, the resource may now also be used to guide rehabilitation clinicians and support them to drive sustainable change in rehabilitation settings through helping people with brain injury to build their social media mastery and to take part in supportive online networks.

Author Contributions

Melissa Brunner: Conceptualization (Lead), Writing – original draft (Lead), Writing – review & editing (Lead). Rachael Rietdijk: Conceptualization (Lead), Writing – original draft (Lead), Writing – review & editing (Lead). Petra Avramovic: Writing – review & editing (Equal). Emma Power: Writing – review & editing (Equal). Melissa Miao: Writing – review & editing (Equal). Melissa Miao: Writing – review & editing (Equal). Nick Rushworth: Conceptualization (Equal), Writing – review & editing (Supporting). Liza MacLean: Writing – review & editing (Supporting). Leanne Togher: Conceptualization (Equal), Writing – review & editing (Equal).

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Appendix

Interview Guides Collaborative design phase: Initial interview guide For people with acquired brain injury: What problems have you encountered with using social media? Has the way you use social media changed since before your accident? What kind of social media platforms do you use? Why do you prefer this platform over others? What are the good things you've found about using social media? Do you avoid using any platforms? Why? Do you have any concerns using social media?/What is challenging about interacting on social media? What information would be helpful for you? Are there any strategies that you have found helpful? For everyday communication partners: Have you had any concerns about a person with traumatic brain injury (TBI) using social media? Example? Do you interact with someone with a brain injury over social media? What are some strategies you have found helpful in supporting a person with TBI use social media? What are some challenges or barriers you have noticed for a person with TBI when using social media? What information do you need as a carer to support people with brain injury with using social media? What do you see as the opportunities/risks of people with brain injury using social media? For professionals including speech pathologists: Have you had any concerns about a person with TBI using social media? Example? Do you interact with clients over social media, for example, a closed Facebook group? An online forum? Would you consider the use of social media a rehab goal? Is this something you have worked on before? How did it go? What are some strategies you have found helpful in supporting a person with TBI use social media? What are some challenges or barriers you have noticed for a person with TBI when using social media? What information do you need as a professional to support people with brain injury with using social media? What do you see as the opportunities/risks of people with brain injury using social media? Collaborative design phase: Follow-up interview guide What are you thinking, as you look at this page? Which step in using this tool would be most difficult for people? What is one thing we need to change? What is your first impression about what this tool looks like? Can you share something that piqued your interest. Pilot study: Follow-up interview guide Did you get out of the course what you were hoping to learn? If not, what areas were missed? What was the most significant thing you took away from the course? How did you find accessing and navigating the course activities? Which activities were most helpful? Which activities weren't helpful? How did you feel about the length of the course? We're aware that it's not always easy for people to complete an online learning course-how did this go for you? Have you got any ideas about how we could support people to make progress with the course? What types of people would you suggest the course is good for? What types of people would the course not be good for?