



THE UNIVERSITY *of* EDINBURGH

Edinburgh Research Explorer

The Digital Support Platform: a qualitative research study investigating the feasibility of an internet-based, post-diagnostic support platform for families living with dementia.

Citation for published version:

Killin, L, Russ, T, Surdhar, S, Yoon, Y, McKinstry, B, Gibson, G & MacIntyre, D 2018, 'The Digital Support Platform: a qualitative research study investigating the feasibility of an internet-based, post-diagnostic support platform for families living with dementia.' *BMJ Open*. DOI: 10.1136/bmjopen-2017-020281

Digital Object Identifier (DOI):

[10.1136/bmjopen-2017-020281](https://doi.org/10.1136/bmjopen-2017-020281)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Publisher's PDF, also known as Version of record

Published In:

BMJ Open

Publisher Rights Statement:

This is an Open Access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>

General rights

Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact openaccess@ed.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.



BMJ Open Digital Support Platform: a qualitative research study investigating the feasibility of an internet-based, postdiagnostic support platform for families living with dementia

Lewis O J Killin,^{1,2} Tom C Russ,^{1,2,3} Sushee Kaur Surdhar, Youngseo Yoon,⁴ Brian McKinstry,⁵ Grant Gibson,⁶ Donald J MacIntyre^{1,2}

To cite: Killin LOJ, Russ TC, Surdhar SK, *et al.* Digital Support Platform: a qualitative research study investigating the feasibility of an internet-based, postdiagnostic support platform for families living with dementia. *BMJ Open* 2018;**8**:e020281. doi:10.1136/bmjopen-2017-020281

► Prepublication history and additional material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2017-020281>).

Received 27 October 2017
Revised 14 March 2018
Accepted 20 March 2018



¹Centre for Clinical Brain Sciences, University of Edinburgh, Edinburgh, UK

²NHS Lothian, Edinburgh, UK

³Alzheimer Scotland Dementia Research Centre, University of Edinburgh, Edinburgh, UK

⁴College of Medicine and Veterinary Medicine, University of Edinburgh, Edinburgh, UK

⁵Usher Institute for Population and Health Sciences, University of Edinburgh, Edinburgh, UK

⁶Faculty of Social Science, University of Stirling, Stirling, UK

Correspondence to

Lewis O J Killin;
lewiskillin@nhs.net

ABSTRACT

Objectives To establish the feasibility of the Digital Support Platform (DSP), an internet-based, postdiagnostic tool designed for families living with a diagnosis of dementia.

Design Qualitative methods using normalisation process theory as an analysis framework for semistructured interview transcriptions.

Setting A community care setting in the South-East Scotland.

Participants We interviewed 10 dyads of people with Alzheimer's, vascular or mixed dementia (PWD), and their family carers, who had been given and had used the DSP for at least 2 months.

Results Our analysis revealed that the DSP was predominantly understood and used by the carers rather than PWD, and was used alongside tools and methods they already used to care for their relative. The DSP was interpreted as a tool that may be of benefit to those experiencing later stages of dementia or with physical care needs. Carers stated that the DSP may be of benefit in the future, reflecting a disinclination to prepare for or anticipate for future needs, rather than focus on those needs present at the time of distribution. PWD spoke positively about an interest in learning to use technology more effectively and enjoyed having their own tablet devices.

Conclusions The DSP was not wholly appropriate for families living with dementia in its early stages. The views of carers confirmed that postdiagnostic support was valued, but emphasised the importance of tailoring this support to the exact needs and current arrangements of families. There may be a benefit to introducing, encouraging, providing and teaching internet-enabled technology to those PWD who do not currently have access. Training should be provided when introducing new technology to PWD.

BACKGROUND

Dementia's impact on society is well understood, and although there are important benefits to its timely and early diagnosis,¹

Strengths and limitations of this study

- A focus on everyday barriers and issues that affect the uptake of internet-based interventions complements and elaborates on previous research about these interventions' usability and usefulness.
- A focus on early stages and families with a recent diagnosis revealed the priorities of those who are making new arrangements to accommodate dementia into everyday life, but might benefit most from postdiagnostic support.
- Homogenous sample of people with dementia (PWD)–carer relationships reduces the generalisability of our findings.
- A lack of dedicated technology training and support probably posed a barrier to some PWD and their families using the Digital Support Platform fully.

postdiagnostic support is similarly important, with some families living with dementia in fact reporting a sudden decline in attention and services, a so-called, 'post-diagnostic cliff'.² Accordingly, the UK Department of Health has stated its ambition to deliver better quality postdiagnostic service in its 2016 joint declaration of dementia care and support.³ Similarly, in its 2016–2019 National Dementia Strategy, the Scottish Government has stated its aspiration to establish good quality, consistent postdiagnostic support for families living with dementia,⁴ having previously stated that technology may help families access the information and services that are necessary for effective care and support.⁵ To this end, it funded and supported initiatives such as the Technology Enabled Care (TEC) programme, which aims to improve national health by making better use of currently existing technologies.

Our current understanding of internet-based interventions is that they may alleviate outcomes such as depression, distress and improve quality of life in carers,^{6,7} and recent evidence from the Digital Alzheimer's Centre (DAC) suggests that these interventions can generally be useable and useful.⁸ However, in contrast to psychological postdiagnostic interventions (eg, ref 9), there are relatively few examples of studies of how internet-based interventions are used in everyday settings, how they alleviate or facilitate the work associated with living with dementia and consequently how they are evaluated. These qualitative data are informative, as they reveal the difference between an intervention's predicted use and its actual use in the home, as it is adopted to suit current care arrangements outside of a clinic or 'lab'. This process has been referred to as the 'domestication' of technology.¹⁰ Understanding this negotiation between intended and actual use reveals potentially unmet needs and barriers to uptake that can be considered in the development of future interventions, and, more broadly, addresses a criticism that research often fails to appreciate the complex nature of living with dementia.¹¹

The Digital Support Platform (DSP) was developed by NHS Lothian and the University of Edinburgh, with funding from TEC, to create an internet-based, postdiagnostic support tool for families who had recently received a diagnosis of dementia. The DSP made use of three different technologies developed to give families information about the condition and community resources, as well as facilitating informal and paid caring. The DSP was designed in line with the TEC's incentive to make use of currently existing technologies. The use of three technologies allows a greater range of functions than any one in isolation, and their related, but not identical, purposes meant they were suitable to combine to provide a complementary support platform. This contrasts with other dementia platforms such as ALADDIN (A technology pLatform for the Assisted living of Dementia eLDERly INdividuals and their carers¹²) and the DAC,⁸ which have been developed as independent 'one-stop' technologies or portals.

In this study, our aim was to determine the feasibility of improving the quality of life of people with dementia (PWD) and their families with the DSP by adopting a qualitative approach, focusing on the needs of families recently diagnosed with dementia, the work they do to address these needs and how the DSP may have been used to this end.

METHODS

DSP recipients and study target population

The DSP was distributed between May 2016 and May 2017 to families living with a diagnosis of any type of dementia in the NHS Lothian health board. Families were primarily identified through Alzheimer Scotland Link Workers,¹³ who are community-based, postdiagnostic support workers allocated to families after they

receive a dementia diagnosis. In line with the 5 Pillar Model of Post Diagnostic Support, link workers are responsible for providing families with information about (1) community connections, (2) peer support, (3) future care, (4) dementia and its symptoms and (5) future decisions.

For this feasibility study, we identified a subset of families under the following inclusion criteria: living with a diagnosis of Alzheimer's disease, vascular dementia or mixed aetiology, where the (PWD) had capacity to consent and a carer who could act as a study partner.

Distribution and study recruitment procedure

Link workers agreed to raise and discuss the DSP as a service that families could access. Link workers identified families with dementia who expressed an interest in the DSP, and forwarded their contact details to the DSP team. The DSP was also publicised in the community as a service through posters and leaflets, and so some families were self-referred. The DSP was also available to volunteers registered on Join Dementia Research, an online national research interest register¹⁴ and staff members of NHS Lothian.

Intervention

The DSP is composed of three technologies:

1. *Living It Up* (NHS Scotland)—a well-being portal designed to provide information and advice about conditions (including, but not limited to, dementia) and relevant community resources located near the user's location.
2. *Jointly* (Carers UK)—a care coordination service that defines an informal network or 'circle' of care for a person living with dementia (including, eg, relatives, friends and professional carers), allowing all members of the circle to communicate and access shared tools and functions, such as a calendar, address book or to-do list.
3. *ClickGo* (Carr Gomm)—a support appointment scheduling interface for families with a statutory package of care in place. Appointments, requested by the user/family, can be confirmed or modified by the care provider back office. Information regarding the care plan is also shared via ClickGo, including the remaining monthly support budget, profiles for members of the care team and current progress on predefined outcomes.

A member of the team would ascertain whether the family would be interested in receiving the DSP. In addition to this, they ascertained whether they were using packages of care, and what internet-enabled technology was present in the home and who used it; this informed what computers or devices would require the DSP, and whether a tablet with mobile data would be needed. In addition to the distribution service, eligible families were also invited to participate in the feasibility study, which was introduced as an opportunity to provide detailed feedback about the DSP.



Distribution visits lasted for up to 1 hour on average. LOJK would install, register and demonstrate all necessary aspects of the platform onto the family's device (or provided tablet). Chloe Burton demonstrated a ClickGo account for families with a care package in place.

While the broad needs and capabilities of different families were taken into account at the point of distribution, the DSP was not tailored to address specific needs. We anticipated that the DSP would provide a range of tools and functions that would address said needs.

Families consented to the study were contacted at least 2 months later by telephone by LOJK to organise the qualitative interviews at the family home. At this point, LOJK would also ask permission for a medical student to be present and to conduct one of the interviews.

A family's digital literacy was not formally assessed until the interview phase (see online supplementary materials).

Interview procedure

Semistructured interviews were conducted by LOJK (post-doctoral researcher), YY and SKS (medical students). Two members of the research team attended interview appointments so that carers and PWD could be interviewed simultaneously and separately in different rooms in the family home. There were no cases where a third party was present for any interview. The structure for the interviews was the same for PWD and carers (online supplementary materials).

Interviews naturally lasted between 15 and 30 min, were audio recorded and transcribed by the interviewer with one exception due to a time restriction, and was transcribed by a different interviewer (DSP005 PWD). Field notes were made where an interviewee referred to a specific piece of software or hardware that was not known

to the interviewers. All interviewers received training on qualitative and interview methods.

Patient and public involvement

Patients and the public were not involved in the development, design, recruitment or conduct of this study.

ANALYSIS

The analysis plan was discussed once all interviews were conducted and transcribed. Although there were sufficient data to conduct a thematic analysis, an analytical framework approach based on normalisation process theory (NPT¹⁵) was chosen. NPT was agreed as being relevant to our study aims as it outlines and identifies the ways in which organisations (in this instance, families as support networks) (A) work to make sense of a new intervention, (B) organise themselves to implement an intervention, (C) how they use it alongside current methods and (D) how they evaluate its efficacy. Respectively, these translate into the NPT's four core constructs of (A) coherence, (B) cognitive participation, (C) collective action and (D) reflexive monitoring. These constructs were used to structure our analysis and results, and are described with exemplars in more detail in [table 1](#). All transcripts were coded by LOJK.

RESULTS

We received 89 referrals, of which 48 families were seen in person and given the DSP. Only 16 families (33.3%) were consented in the full study, with a lack of capacity to consent being the most common reason for ineligibility.

Table 1 Interpretation and application of the normalisation process theory constructs

Construct	Interpretation	Example
Coherence	Coherence or 'sense-making work' details how families understand the purpose of the DSP and how it may aid work associated with dementia care (<i>Internalisation</i>). This may be interpreted as how it may benefit an individual (<i>Individual Specification</i>) or the family (<i>Communal Specification</i>). Coherence also includes how the DSP is differentiated from current methods used to complete said work (<i>Differentiation</i>).	Q4
Cognitive participation	Cognitive participation or 'relational work' details how families organise themselves to create a network of individuals who participate in using the DSP. This organisation includes identifying key participants (<i>Initiation</i>) and reorganising or redistributing the work present within existing relationships (<i>Enrolment</i>). Cognitive participation also includes how individuals feel that it is right for them to be involved with the DSP (<i>Legitimation</i>) so that they may continue to use it (<i>Activation</i>).	Q15
Collective action	Collective action or 'operational work' is how families interact with the DSP (<i>Interactional Workability</i>) and with each other (<i>Relational Integration</i>). Collective action can also refer to the overlap between the demands of the DSP and an individual's capabilities (<i>Skillset Workability</i>). It also includes how resources and support are allocated towards families to help them use the DSP (<i>Contextual Integration</i>).	Q23
Reflexive monitoring	Reflexive monitoring or 'appraisal work' is how families access or review information (<i>Systematisation</i>) to appraise the DSP collectively or individually (<i>Communal and individual Appraisal</i>). Appraisal is used to refine the DSP (<i>Reconfiguration</i>).	Q35

DSP, Digital Support Platform.

Table 2 PWD characteristics

PID	Gender	Diagnosis	Study partner relationship	Referral	Technology set-up
DSP001	Male	AD	Spouse	JDR	Two tablet computers and PC
DSP002	Male	Mixed	Spouse	JDR	Study partner's PC and tablet provided for participant
DSP005	Female	Mixed	Daughter	Link worker	Tablet provided for participant
DSP006	Female	Mixed	Daughter	Link worker	Tablet provided for participant
DSP008	Male	Mixed	Spouse	Link worker	Two tablet computers and a PC
DSP009	Male	AD	Spouse	Link worker	Tablet provided for participant
DSP011	Male	AD	Spouse	Link worker	Study partner's laptop and participant's own tablet
DSP012	Male	Mixed	Spouse	Link worker	Study partner's laptop and participant's own tablet
DSP013	Male	AD	Spouse	Self-referral	Tablet provided for participant
DSP014	Male	Mixed	Spouse	Link worker	Participant's PC

AD, Alzheimer's disease; DSP, Digital Support Platform; JDR, Join Dementia Research; PID, Participant ID; PC, personal computer; PWD, Person With Dementia.

Participants

Ten PWD–carer dyads were interviewed; the characteristics of the PWD are described in [table 2](#). The average age of PWD at the point of distribution was 74.5 years old (range 66–81). After these interviews were transcribed and analysed, it was agreed in a study meeting that 10 dyads represented a point of data saturation. No participants refused to participate or dropped out from the interview appointments.

All participants' quotes are given in [table 3](#).

Coherence: understanding the DSP

From the perspective of PWD, the DSP was not fully understood. At a practical level it was unclear as to whether the 'platform' referred to the hardware or software (*Q1*). At a conceptual level, adopting the DSP necessitated a confirmation or acceptance of a diagnosis some PWD were reticent to accept or were not aware of (*Q2*, *Q3*).

Therefore, most sense-making work was done by carers rather than by PWD, and the DSP was identified to be of benefit to the work carers do rather than the work PWD do (*Q4*). However, the idea of what caring work entails was not very well defined when caring for someone with dementia in its relatively early stages (*Q5*).

To this end, the DSP was understood as something that was of benefit to families experiencing later stages of dementia. In the case of Living It Up, a family carer reflected on a friend whose husband had had to drop activities due to his dementia, and contrasted this to her own husband's activities (*Q6*). In this sense, Living It Up was understood as an aid for other individuals who had less autonomy over their current activities and interests. This was echoed by other families who used Living It Up to attend community activities (eg, dementia cafés) or read personal stories, but perceived that these resources did not overlap with their current needs (*Q7*, *Q8*).

Similarly, Jointly was appreciated as a tool that would be useful should caring needs expand beyond the control of current communication methods (*Q9*).

The DSP was also seen as an auxiliary method for completing care work. In the case of Living It Up, two families noted that they would have found the site independently as one of many returned by a search engine (*Q10*, *Q11*). Jointly was also incorporated into current methods of communication and time-keeping (*Q12*, *Q13*). Aspects of the DSP were therefore used, but not as the primary methods of completing care-related work.

Cognitive participation: who uses the DSP?

Although all aspects of the platform were designed to be relevant to PWD, carers identified themselves as the main member of the family that took the lead in using and promoting the DSP (*Q14*), as did PWD (*Q15*, *Q16*). As a result, carers would encourage PWD to use the DSP, but experienced resistance that ranged from apathy (*Q17*) to anger and frustration (*Q18*, *Q19*), as they felt that the DSP was relevant to carers and not them (*Q20*) or felt that the DSP highlighted their diagnosis, echoing the fundamental conceptual barrier some PWD expressed at the point of coherence (ie, *Q2*).

Collective action: experience using the DSP

Carers reported that they had sufficient previous experience with technology to use the DSP, which therefore translated into actual use of it. For example, after the distribution visit, some carers established a Jointly circle and invited specific members of the family. In one case, a carer used Jointly to facilitate a request (*Q21*), but, more commonly, there was a lack of sustained use after establishing a circle (*Q22*).

By contrast, PWD demonstrated varied confidence and experience with technology. In one example, a PWD had

**Table 3** Extracts from qualitative interviews

Number	Quote
1	[P]: The DSP includes this piece of equipment here, doesn't it? [YY]: Yes. [P]: Well that's the starting point. And that I think is very important for somebody like me, but I don't have enough information that I need to advance on that. (DSP009 PWD)
2	He doesn't want to go into group chat because... it sounds silly, but he doesn't want people to know he has Alzheimer's. (DSP002 Carer)
3	I don't know anyone living with dementia, quite honestly. (DSP013 PWD)
4	I couldn't see it being helpful for my husband. But I could see it could be helpful for me... I can see how it can be an advantage for a carer. (DSP001 Carer)
5	I don't think we've got... needs. We don't have any physical problems or any other problems that needs anybody to support us... I honestly don't think my husband has got dementia. (DSP009 Carer)
6	... he used to fish and he used to...it was all outdoor things but nothing that he can do now. Nothing that he's been able to keep up with. Whereas [P] has had some interested that he can keep up with, so I could see that Living It Up would be useful for some people. But at the moment, we don't need it. (DSP001 Carer)
7	I says to the lassie ken what really gets me is there's naewhere for someone younger, it's aw for people that are older and the disease is quite far along the way. (DSP011 Carer)
8	I felt that a lot of the cases were people who were far advanced in the Alzheimer's than [P] is. So I didn't really think... I would say I didn't really think it was relevant but that's the wrong word. (DSP002 Carer)
9	...mum doesn't have carers coming in so that part of the platform probably isn't all that helpful to us, you know, if you had lots of different people coming in then that would be helpful but we're not really at that stage now. (DSP005 Carer)
10	[LOJK] So this was Living It Up... [P] I might have got that through on the computer, cause quite often I just go to 'dementia' and see what pops up. This may be one of them that came up. (DSP001 PWD)
11	The only way I think I'd use [Living It Up] is if I Googled something and it came up as the website that that information was on, so it probably would be if that came up by chance. (DSP005 Carer)
12	[LOJK] How about Jointly? Did you feel that there was anything there that you liked about it? [C]: Possibly that it was good to know that we could call on people who were members of the circle, but you could do that anyway, y'know. (DSP009 Carer)
13	[LOJK]... if you put something on Jointly would you... rely solely on Jointly, do you think. [C]: No. [P] puts it on his calendar, I put it on the phone. I put it on the calendar on my phone. And if it's like an appointment or if we've got to be somewhere I put a reminder on, so it flashes up. [LOJK]:...It's almost written down in three places. [C]: Four, because it also goes up on the calendar on the wall. (DSP002 Carer)
14	[C]: And if I could get [P] intae it—I think maybe if [P] seen me on it and I said 'what about this' then he would take over I could just leave I'm with that and he can go through... You know once I showed him just click onto that and it'll take you right into that eh. [LOJK]: So you think he would need to follow your lead? [C]: Aye, yeah. (DSP011 Carer)
15	As I say, it's [C] who pushes me on this, and I—I focus on financial affairs and things like that and she focuses on this and between the two of us we—we sort of know what I think mostly folk are wanting to do. (DSP001 PWD)
16	[LOJK]: So, could you tell me maybe some of the reasons you didn't feel comfortable using [Living It Up and Jointly], or um, that you found that you weren't using them? [P]: I just let [C] use them. (DSP008 PWD)
17	He doesn't want to, he's not keen on learning anything new. I did show him the Living It Up one and said tell me what you think about it. He says ok, just leave it there and I'll have a look at it so the next time, about half an hour later... I said what do you think of it? He says it's alright. He doesn't want to learn anything new. It's just the stage he's at. (DSP001 Carer)
18	[LOJK] If [P] sort of isn't on board with it, does that, do you think that also prevents you from getting into it as well? [C]: I've been told. [LOJK] Right. Not to—[C]: I've been told not to. (DSP002 Carer)
19	If I keep on at him, he blows. (DSP014 Carer)
20	'Are you looking after someone?' Well, I'm not. So well, I kind of said, 'oh, that's really not for me.' (DSP013 PWD)
21	The Jointly one, now that really could be helpful and I started using it... the first one I did was urm 'Dad and I are going up to Aberdeen and need a lift up to the bus station'... and immediately, of course all 4 got it, and 2 of them said sorry I can't and the other 2 said I can, I'll do the one and you do the other. (DSP001 Carer)
22	Member of the circle, yeah, mhmm. Yeah, they both agreed [to join Jointly]. But since then, we honestly haven't done anything. (DSP009 Carer)

Continued



Table 3 Continued

Number	Quote
23	cos he messed it up, I think a couple of days after Lewis had came, he messed it up and I says, 'What have you done?' (DSP012 Carer)
24	Just in the first place to know how to use it. I mean, like I say, switching it off was a nightmare. And I thought who I do I phone, well I phoned the next door neighbour but I don't know. (DSP006 PWD)
25	I don't have any skills whatsoever in computers, apart from switching it on and switching it off. That's the size of it. I would like very much if there was a class I could attend for something very basic. (DSP009 PWD)
26	[SKS]: Is there anything that you didn't like about the tablet? [P]: No, no. Except inexperience of using it. I went to the library and had a wee lesson there about emails. Because I wasn't good at it, and one of the girls was good. And if I need any help I just go to the library, and they're good. (DSP013 PWLD)
27	But she's not a teacher—she finds it very difficult... And it can be a bit upsetting as well. She's much better than me but she's not very happy trying to take me by the hand and leading me through the procedures and she gets very frustrated as well. (DSP009 PWD)
28	As I say, if—if somebody had gone through it with me at the beginning, that would have been helpful. Just sat down and said now, you know, this is what you can do with it and that's what you can do with it. I think that would have been helpful. (DSP001 Carer)
29	And so, I should have acted on it, you know, sooner rather than trying to do it later urm because it had just gone. And urm, I should, I really should have phoned up Lewis and phoned him up and said 'Look, I'm not really sure of this' because I think with [P]'s condition, I think I should really be able to do a bit more urm (1) to help him. (DSP012 Carer)
30	And I compared what I'm doing just now with what they're describing and I was finding what I was doing which I've already explained to you, which I felt was good for me and more what I am used to and it was more useful... (DSP009 PWD)
31	[C]: Ah think it was good, there's plenty—there's information, activities, people's stories and I found that quite good, mainly because I was nosy but I thought it's good to hear how other people are living with what we're living with eh. (DSP011Carer)
32	I think seeing how, how uh, dementia can progress and people being in real need[?] and I just felt, I dunno If you want to face that really and you keep thinking, you know there's nothing wrong with us or with [P]. (DSP009 Carer)
33	I think I would like to try and do something urm (1) cos if it's charting [P]'s progress, I think I would be interested in that you know try to (inaudible) how I'm coping with it as well, so it would be good to write it, actually write it down almost, or record it somewhere. (DSP012 Carer)
34	Could you have something in it like, 'early stages' or... ken I think when they're in the early stages there's no really a big difference in them. (DSP011 Carer)
35	Now that's extremely helpful. So that made me think, yeah this could be really helpful for a carer. Now I'm talking as a carer now... I'll try and use them if I can just make the time. (DSP001 Carer)
36	Well it was interesting to read other people's ways of coping with dementia problems. That, once again, I just felt they weren't appropriate to our life or needs at the moment. (DSP009 Carer)
37	But I'm not discounting the fact that it's there and it can be used...it gives me a feeling that there is that support there should I need it. It's like a failsafe, if you like. (DSP002 Carer)
38	No, I think that the support is there, Sushee. I'm just not using it at the moment. (DSP012 Carer)
39	No, no. But then there's bound to be a lot of people who don't have link workers. It—it just depends on whether you need the support of somebody else. And [P] doesn't—he wouldn't like that. (DSP013 Carer)
40	Well we've only got [link worker] that comes. [Link worker] is the only one that comes here. Cause at the moment I don't think we need any more. I dunnae want to have it pushed in our face, the dementia, eh. (DSP011 Carer)
41	I'm not here feeling sorry for myself, I can get into (the tablet) and the day goes quicker... I dunno what to say to be honest. I love it. I love it. (DSP002 PWD)
42	He's thrilled with it, absolutely thrilled. (DSP013 Carer)
43	[YY]: Excellent. And are there any aspects of the apps Living It Up and Jointly that you'd probably like to use again? [P]: I don't understand them, you see, if somebody showed me what I'm supposed to do then fine, I'll have a go at it, but I don't understand what I'm supposed to do. (DSP002 PWD)

DSP, Digital Support Platform; PWD, Person With Dementia.

experience that was comparable to their relative's, but other PWD estimated their skillset to be quite poor, or felt that use of technology was out of their grasp at the

time of the interview. In one case, a PWD demonstrated an *OwnFone*¹⁶ as the piece of technology they use to maintain contact with their friends and relatives, implying that



a standard mobile phone would be too taxing to use. As a result, PWD's use of the DSP was met with practical barriers in both software and hardware difficulties (Q23, Q24).

PWD who felt they were not confident with technology were nonetheless interested in obtaining support. PWD were keen to clarify what support they needed or had obtained, for example, gaining an understanding of basic computing through an ad hoc tutor or class based in the community (Q25, Q26). A desire for independent forms of support contrasted with support that was currently available. For instance, one PWD noted that his carer was unable to provide the necessary time and effort to help him (Q27). A different family asked for technological help from a younger member of the family who visited once a week, and one individual called on their neighbour when they were unsure how to use the provided tablet (Q24).

This need for a dedicated support individual was echoed by some carers, who requested a single set-up session to take place, or a dedicated individual who could provide support (Q28). However, although contact information was provided for families to get in touch in the event of a hardware or software problem, one carer described their hesitation to contact the DSP team (Q29).

Reflexive monitoring: appraising the DSP

Families appraised the DSP by reflecting on their experiences using it. Three separate interviews revealed that PWD and carers positively appraised Living It Up for allowing them to compare their stories with those of others' (Q30, Q31). This act of comparison and confirmation was seen in a broader activity a PWD (DSP001) mentioned, where he would use Google to compare his symptoms with those that were associated with dementia and those associated with a medication he was taking.

Several carers understood Living It Up as being relevant to later stages of the disease. In some cases, this meant the DSP introduced a confrontation with the progressive nature of the disease in a way that was difficult to accept (Q32). However, some carers spoke more broadly about their keenness to understand how the disease may progress, what to anticipate and how they may monitor this change (Q33). Ultimately, however, families felt there was an absence of information about early or mild changes on Living It Up (Q34).

More broadly, the DSP was appraised as a useful intervention, but not used fully given constraints of time (Q35) and its lack of relevancy to their needs at the point of distribution (Q36). However, the DSP was thought of as something that could be used in the future as needed (Q37).

Ultimately, this appraisal spoke to a broader appraisal of support services. Families noted that they were aware of support that was available, but wished to approach this when they needed it (Q38) and when they felt it was appropriate to do so (Q39, Q40).

However, PWD who were distributed tablets responded very favourably on their ability to access apps and websites

(Q41, Q42). This contrasted with their appraisal of the constituent technologies of the DSP (Q43), and the fact that they already had access to the internet through their carer's device.

DISCUSSION

Statement of principal findings

Carers were the primary users and motivators behind the DSP. They understood it as something suitable for families experiencing later stages of dementia or with more physical care demands. In this way, the DSP was interpreted as a 'failsafe' and could be referred to later as the disease progressed and circumstances changed. However, for those in the earlier stages of the illness, the DSP was not relevant to their everyday lives. Specifically, families felt that their current methods (eg, use of paper calendars and to-do lists) were sufficient for addressing the work associated with early dementia, and the DSP was used as an auxiliary tool at best. Carers' evaluation of the DSP included the theme of support being available and accessed only when necessary, and expressed that constraints on time prevented them using the DSP fully. PWD tended not to use the DSP, but expressed a wish to learn to use technology and responded positively to having their own tablet, enjoying features popular with the general public such as YouTube and Skype. Some dementia-related symptoms, such as apathy, may also have affected uptake and engagement with the DSP.

Strengths and limitations of the study

This study presents a qualitative account of how families living with dementia approached an internet-based post-diagnostic support service, and captured the disparity between the DSP's intended and actual use. In doing so, this study reveals barriers and desired aspects of the platform that could be expanded to improve the uptake of future interventions for this population, and can inform the development of other online support platforms for PWD.

The chosen population of this study—families living with early dementia—is simultaneously a strength and limitation. We chose to focus on those who are most likely to experience the 'post-diagnostic cliff' and for whom a postdiagnostic intervention would be of benefit as they reorganise current arrangements to accommodate dementia. From this, we identified that mild cases of dementia did not warrant physical help or communication between informal and paid carers, which meant that the use of the DSP—and likely similar future interventions—was limited.

Relatedly, the population of families in Scotland is a limitation and strength. Given that the Scottish Government has committed to a high level of postdiagnostic support, the DSP is realistically one of many postdiagnostic support services. This means that we are unable to observe its efficacy in isolation from other forms of



support, but we may argue that our findings contextualise the current level of support as being satisfactory.

Despite the recent nature of their diagnosis, it was common for PWD to not have the capacity to consent. To this end, ethical approval through an Adults with Incapacity REC may have broadened recruitment.

Although PWD were interviewed, we revealed little insight into their use of the DSP. From our results, this is likely to be due to a lack of dedicated technical or learning support that would be necessary for PWD to feel comfortable using elements of the platform alone. However, it should be noted that digital literacy was not formally ascertained until the interview section, where PWD were asked what technology they currently use, or what technology they had stopped using. Future research should attempt to establish this prior to intervention to establish training earlier.

Finally, the choice of NPT as an analytical framework is an appropriate choice for our research question. However, while the choice to use the NPT as a suitable analysis framework was an informed decision between members of the research team, only one researcher applied the constructs to the data.

Strengths and limitations in relation to other studies

Our study can be interpreted as a complementary report to the usability and usefulness report of the DAC.⁸ Here, the authors' analysis was drawn from participants who had been exposed to and trained to use the DAC in a memory clinic. By contrast, the DSP represents a community-based intervention distributed with a one-off demonstration. The current study demonstrates a limitation by contrast, as more training on the DSP may have improved the odds of further use and insight into the DSP. However, it is of note that use of the DAC was still relatively infrequent, as only 51.4% of survey respondents reported using it at least twice. Indeed, we revealed similar preventable technical (eg, logging in) and conceptual (carers and patients reporting 'no need' to use the DAC) barriers to the DAC study team. These similarities suggest that common, fundamental barriers to intervention uptake exist, and they cannot be alleviated by training alone. The results of the present study suggest that conceptual understanding of an intervention and its relevance to present needs are significant barriers of this kind. In context, however, our findings are drawn from fewer observations than Hattink *et al* (2016), who analysed results from 287 survey respondents (88 PWD, 199 carers). Therefore, while we identified similar issues between the DAC and DSP, a larger study sample of survey respondents would be necessary to clearly quantify and compare the prevalence or distribution of these issues.

Our results echo a point of discussion from Milne and colleagues¹⁷ regarding when an intervention should be introduced during dementia's progression. The authors—who investigated a GPS fencing system—noted that families who may have benefited most from the intervention may have already lost confidence in independent

walking. However, investigating the effect of an intervention at an earlier stage was likely to reveal small or negligible effect sizes. Similarly, the DSP may not be best suited for work associated with early dementia, but it may not be appropriate to introduce a new technology to PWD in more severe stages of dementia. Ultimately, both studies suggest that early *introduction* of technology may be beneficial, but may not be *effective* until families use the intervention to address a new change in circumstances and independence. This emphasises that longitudinal engagement with families may be necessary to achieve potential benefits of technology.

Our study is an elaboration on the 'arrangements' research that details the work elderly individuals do to accommodate telecare.^{18 19} Here, technology is not necessarily used as intended, but is rather adapted into current methods of work or care. For instance, Jointly was appreciated as an additional form of appointment reminders for one family, rather than being used as a definitive calendar. Overall, this study confirms that technologies are usually 'domesticated' or 'tinkered with' to practically fit current methods, rather than adopted wholesale.¹⁰

Critically, we have demonstrated examples where PWD have engaged and responded positively to basic internet-enabled technology. This is an unexpected finding, especially given that some PWD already had access to these technologies, but may have perceived the family computer—or household responsibility for technology—as being their relative's. This suggests that PWD may benefit from the introduction of personal devices and necessary tuition, and potential to enhance our current understanding of the reported challenges PWD experience with technology, or with approaching technology.^{8 20}

Unanswered questions and future research

In its present state, the DSP was not seen as relevant to families living with early stages of dementia, and did not encourage networking in real life. Potentially, if the DSP was modified to provide more information about resources or events more suited for those in earlier stages, this may increase families' engagement with community activities. However, this is not known at present. It is not clear how the DSP will benefit families living with more severe stages of dementia, and how the families observed here will refer to its components as their needs change; ultimately this cannot be known without follow-up research, but current results suggest that the DSP may be of benefit as everyday care work becomes more burdensome. Relatedly, it is not known whether the DSP would be of benefit to families where the primary relationships are less proximal than those observed here (ie, mainly spousal relationships living in the same household). Similarly, it is not clear whether the DSP would be relatively of more benefit to those living in rural parts of the country, where postdiagnostic services are reported to be less accessible.²¹ Where we have posited the role and benefit of tuition, we have not assessed barriers specifically associated with technology training for PWD; these could



only be understood with further research focused on this topic. Lastly, we anticipate that some of the barriers we have identified here may change or be less relevant to younger generations who are more familiar with technology. Future research would allow a formal assessment of this change.

The meaning of the study

Broadly, the DSP was not highly suitable at the time of distribution, but was considered to be an additional form of support that could be used when necessary. The differential use of the DSP across our population reflects previous guidance that the needs of a family are idiosyncratic²² and multifactorial,¹¹ and our findings confirm that support resources should be made available to families for them to choose and use as they feel it is necessary. The unexpected finding that PWD were keen to engage with internet-based technology despite having it in the household already entails that we need to be critical of our assumptions of how families living with dementia use and access technology and the internet, and the potential benefit of addressing these assumptions.

Acknowledgements The authors thank all the participants and link workers for their time and effort in distributing, using and evaluating the DSP, and Graeme Cumming of NHS Lothian and Keith Willcock of the Scottish Government for their support. We thank Dr Lucy McCloughan for her assistance as the project's manager and administrator. We also thank Carr Gomm and Carers UK for their involvement in the project, with particular thanks to Chloe Burton for her help in distribution visits and management of ClickGo. DJM acknowledges the financial support of NHS Research Scotland (NRS), through NHS Lothian, and is an NRS clinician.

Contributors DJM conceived the project, supervised LOJK on the project, informed the study design and contributed to the writing of the manuscript. LOJK informed the study design, collected, transcribed and analysed data, and contributed to the writing of the manuscript. TCR informed the study design and contributed to the writing of the manuscript. SKS and YY collected and transcribed data. GG and BMCK supervised with the analysis plan and contributed to the writing of the manuscript.

Funding Funding for the project came from the Scottish Government's Technology Enabled Care Fund, and the Digital Health Institute (Grant Reference: Dementia (Post Diagnostic) Digital Platform).

Disclaimer The funders were not involved in the study design; in the collection, analysis and interpretation of the data; in the writing of the report; or in the decision to submit the paper for publication.

Competing interests None declared.

Patient consent Not required.

Ethics approval NHS South East Coast–Brighton and Sussex REC Proportional Review Sub-Committee on 8 April 2016 (REC REF: AC16033).

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement Researchers who wish to access unpublished sections of the transcripts may access them by contacting the corresponding author.

Open Access This is an Open Access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>

© Article author(s) (or their employer(s) unless otherwise stated in the text of the article) 2018. All rights reserved. No commercial use is permitted unless otherwise expressly granted.

REFERENCES

- Dubois B, Padovani A, Scheltens P, *et al.* Timely diagnosis for Alzheimer's disease: a literature review on benefits and challenges. *J Alzheimers Dis* 2016;49:617–31.
- Dodd E, Cheston R, Ivanecka A. The assessment of dementia in primary care. *J Psychiatr Ment Health Nurs* 2015;22:731–7.
- UK Government. Joint declaration on post-diagnostic dementia care and support (8th January 2016). <https://www.gov.uk/government/publications/dementia-post-diagnostic-care-and-support/dementia-post-diagnostic-care-and-support>
- Proposal for Scotland's national dementia strategy 2016 – 19. 2016 <http://www.gov.scot/Resource/0049/00497716.pdf>
- Scotland's National Dementia Strategy: 2013 – 16. <http://www.gov.scot/Resource/0042/00423472.pdf>
- Boots LM, de Vugt ME, van Knippenberg RJ, *et al.* A systematic review of Internet-based supportive interventions for caregivers of patients with dementia. *Int J Geriatr Psychiatry* 2014;29:331–44.
- Jackson D, Roberts G, Wu ML, *et al.* A systematic review of the effect of telephone, internet or combined support for carers of people living with Alzheimer's, vascular or mixed dementia in the community. *Arch Gerontol Geriatr* 2016;66:218–36.
- Hattink B, Drees RM, Sikkes S, *et al.* Evaluation of the digital Alzheimer center: testing usability and usefulness of an online portal for patients with dementia and their carers. *JMIR Res Protoc* 2016;5:e144.
- Sommerlad A, Manela M, Cooper C, *et al.* START (STRAtegies for RelaTives) coping strategy for family carers of adults with dementia: qualitative study of participants' views about the intervention. *BMJ Open* 2014;4:e005273.
- Saborowski M, Kollak I. "How do you care for technology?" – Care professionals' experiences with assistive technology in care of the elderly. *Technol Forecast Soc Change* 2015;93:133–40.
- Dawson A, Bowes A, Kelly F, *et al.* Evidence of what works to support and sustain care at home for people with dementia: a literature review with a systematic approach. *BMC Geriatr* 2015;15:59.
- Torkamani M, McDonald L, Saez Aguayo I, *et al.* A randomized controlled pilot study to evaluate a technology platform for the assisted living of people with dementia and their carers. *J Alzheimers Dis* 2014;41:515–23.
- Alzheimer Scotland. Dementia link worker – Edinburgh. http://www.alzscot.org/services_and_support/search/3188_dementia_link_worker_edinburgh.
- Join dementia research. <https://www.joindementiaresearch.nihr.ac.uk/>
- May C, Finch T. Implementing, embedding, and integrating practices: an outline of normalization process theory. *Sociology* 2009;43:535–54.
- Owfonone. <https://www.myownfone.com>
- Milne H, van der Pol M, McCloughan L, *et al.* The use of global positional satellite location in dementia: a feasibility study for a randomised controlled trial. *BMC Psychiatry* 2014;14:160.
- López Gómez D. Little arrangements that matter. Rethinking autonomy-enabling innovations for later life. *Technol Forecast Soc Change* 2015;93:91–101.
- López D, Sánchez-Criado T. Analysing hands-on-tech care work in telecare installations. In: Prendergast D, Garattini C, eds. *Aging and the digital life course*. New York: Berghahn Books, 2015:179–97.
- Newton L, Dickinson C, Gibson G, *et al.* Exploring the views of GPs, people with dementia and their carers on assistive technology: a qualitative study. *BMJ Open* 2016;6:e011132.
- Innes A, Szymczynska P, Stark C. Dementia diagnosis and post-diagnostic support in Scottish rural communities: experiences of people with dementia and their families. *Dementia* 2014;13:233–47.
- Watts S, Cheston R, Moniz-Cook E, *et al.* Post-diagnostic support for people living with dementia. *Clinical psychology in the early stage dementia care pathway*. London: British Psychological Society, 2014.

BMJ Open

Digital Support Platform: a qualitative research study investigating the feasibility of an internet-based, postdiagnostic support platform for families living with dementia

Lewis O J Killin, Tom C Russ, Sushee Kaur Surdhar, Youngseo Yoon, Brian McKinstry, Grant Gibson and Donald J MacIntyre

BMJ Open 2018 8:

doi: [10.1136/bmjopen-2017-020281](https://doi.org/10.1136/bmjopen-2017-020281)

Updated information and services can be found at:
<http://bmjopen.bmj.com/content/8/4/e020281>

These include:

References

This article cites 14 articles, 2 of which you can access for free at:
<http://bmjopen.bmj.com/content/8/4/e020281#ref-list-1>

Open Access

This is an Open Access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>

Email alerting service

Receive free email alerts when new articles cite this article. Sign up in the box at the top right corner of the online article.

Topic Collections

Articles on similar topics can be found in the following collections
[Qualitative research](#) (735)

Notes

To request permissions go to:
<http://group.bmj.com/group/rights-licensing/permissions>

To order reprints go to:
<http://journals.bmj.com/cgi/reprintform>

To subscribe to BMJ go to:
<http://group.bmj.com/subscribe/>