

RESEARCH BRIEFING

Digital Benefits and Disbenefits Project

PIP SUPPORTERS TOOLKIT

Nº4

A prototype digital intervention for Personal Independence Payment

The *Digital Benefits and Disbenefits* project explored e-government technology-generated remote self-service encounters in welfare benefit public services. Analysis of findings from three studies were used to identify implications for design that intended to reduce harms, negative effects impacting claimants themselves (e.g. time, physical, mental, financial) arising from the digital implementation itself, separate to policy choices (e.g. legislation, regulations) or the inherent nature of digital channels (e.g. availability of devices, internet access, ability to use devices and software). This *Research Briefing Nº4* describes one of the digital prototypes designed and evaluated during the project, which was undertaken to learn more about the harms to claimants arising in Personal Independence Payment and how changes to attenuate harms can introduce new harms or amplify existing harms, to contribute to wider knowledge about digitisation of similar social protection payment public services.

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First published 02 August 2022 at www.digitalbenefits.uk/number4/

Introduction

Earlier steps in the project began to identify negative impacts arising from digitisation design (the harms) on citizens applying for and receiving award payments (claimants). These were used to inform the design and evaluation of two digital prototypes, one for Personal Independence Payment (PIP) in this *Research Briefing N°4*, and one for Universal Credit (UC) in *Research Briefing N°3*. Intentionally, these interventions go beyond concerns about the presented digital interface, to include aspects of claimants' wider ecosystems and how these contribute to service access. This is particularly true for PIP, where the digital version for providing supporting evidence is not offered to all, and most claimants use the paper-based process. The design of this intervention was led by a claimant, and was evaluated by professional advisors, attempted to examine how citizen controlled digital tools could mitigate identified/perceived harms and improve the digital interactions between government and claimants. Together with the earlier work, findings from the design and evaluation of the prototypes contributed to the final harms identified (*Research Briefing N°1*) and implications for design which intend to counter the harms (*Research Briefing N°2*).

Scope of the digital intervention

A PIP claimant made contact directly due to research prior to this project, regarding a hybrid physical-digital diary to help PIP claimants prepare for an advisor assisted interview to complete the PIP claim form (see poster at <https://www.digitalbenefits.uk/pip/>). The claimant wanted to design a digital tool to help gather evidence from supporters. They explained how supporters may be unable to attend the PIP form-filling appointment with the claimant, and possibly do not feel sufficiently confident to write a letter of support, but can provide a useful independent view of a claimant's needs, since some daily needs can become customary and thus may not be recognised or mentioned by claimants themselves. The claimant participant suggested a need for something quicker and simpler than a diary, to gather additional evidence for the claim from these people who otherwise might not be able to contribute.

Design process

Design was undertaken iteratively over a period of three months, to discuss, trial and agree the range, arrangement, language and wording of a questionnaire using MS Forms to try alternatives and implement the final version. The design process also included agreeing an evaluation procedural guide for advisors and an invitation card for claimants to give to supporters requesting them to contribute their evidence through the questionnaire. Additionally, a purpose-built mock assistance organisation web page was made and hosted online, to demonstrate how the invitation card would link supporters via an explanation to the questionnaire form. All these artefacts together are the PS Toolkit.

Summative evaluations were undertaken by people from a single organisation who provide advice to PIP claimants using semi-structured in-person interviews. Each advisor was sent the toolkit materials in advance of interview dates to allow time to read and use the toolkit.

PS Toolkit

The materials created for use in the interviews and parts of the online questionnaire are shown in Figures 1–8.

Figure 1: First page of the briefing document for interviewees providing background to the research project and how the digital prototype was designed



“PIP Supporters”

Research on Personal Independence Payment
Colin Watson, Open Lab, Newcastle University

Background

In 2019 I had developed a hybrid physical–digital diary to help PIP claimants record selected daily living activities, during the period between contacting an advice agency and an assisted form–filling appointment. At the start of lockdown in spring 2020 I began developing a digital–only diary for claimants and requested input from claimants via the PIP Kit website <https://www.pipkit.org.uk>

One person, now “co–designer”, who had not yet made a claim but did have the PIP2 form, made contact with me and expressed their desire to create another thing instead: something for people providing help and support to claimants, to gather information from them to help inform the subsequent advisor–assisted form–filling appointment.

This could be particularly useful if the claimant’s conditions affect their ability to recall and recollect events or their ability to gather evidence is limited, or there are multiple carers/helpers (which we subsequently refer to more generally as “supporters”), or supporters cannot also attend the PIP appointment, or appointments must be done remotely, such as during pandemic restrictions.

Design process

The concept was developed iteratively over a period of three months, all undertaken remotely, with prototypes being shared, updated and tested. The co–designer wanted to ensure the method of collecting information from supporters did not place too much burden on them, as they were already contributing to a claimant’s daily life already, and as such should not require on–going effort such as a diary. Instead a one–time survey method was chosen.

A digital method of information collection was focused on for speed of data collection, although it is recognised the questionnaire could also be created as a paper document. The questions are structured around PIP’s assessment activities, to make it simpler to match up responses.

The co–designer also wanted to ensure the online questionnaire could be shared and re–used by many organisations, so rather than being custom code which would limit its use more, it utilises MS Forms which allows sharing of templates and Office 365 is believed to be commonly available to many organisations.

Figure 2: Second page of the briefing document for interviewees providing an overview of the research activity and a description of how the PS Toolkit would be used in practice



Trial and Evaluation of “PIP Supporters Questionnaire” April 2022

Overview

Thank you for agreeing to participate in this research, part of “Helping Citizens Make Better Use of Appointments with Advice Agencies”, and for previously reading the information sheet and completing the consent form.

You are being asked to provide feedback about an online Supporters Questionnaire used to help gather information from people who support PIP claimants by providing care, encouragement, motivation, watch over them, provide physical help and otherwise provide assistance and support. The information collected would be sent directly to the advice agency so they could use it during a subsequent appointment at which the case-worker/advisor works with the claimant to complete the PIP application form.

We are interested in your general views and opinions about the prototype Supporters Questionnaire, and whether you think it is usable, and whether information received would help you, as an advisor, during PIP form appointments (both face-to-face and remote). We do not want to know anything about particular casework or individuals.

Proposed process for using the questionnaire

The claimant may already have received a paper PIP form to complete, or been requested to complete a PIP form online, or need help to register with DWP first. At this point, an advice organisation’s case-worker/advisor books an appointment to help them complete the form at a later date. If the claimant is in-person, they might be given a physical appointment reminder card, or are sent one by post, SMS or email. The claimant might also be provided with some guidance on what sort of supporting evidence it would be useful have to hand during the appointment. The case-worker/advisor then asks the claimant whether there are any particular people who help them (e.g. assistant, friend, relative, neighbour). If so, the claimant is provided with organisation-branded instruction cards by hand, post or email, with their initials and case reference number added (see next page).

Afterwards, the claimant gives these two-sided instruction cards to relevant people and asks them to complete the survey prior to their form-filling appointment. The survey responses are sent automatically to the advice agency.

Figure 3: Third page of the briefing document for interviewees providing information on the instruction cards created and guidance on the research process

Trial and Evaluation of “PIP Supporters Questionnaire” April 2022

Instruction cards

Research instructions

1. Please read all pages of this document.
2. Open the following website address in a web browser which shows a mock-up of an organisation-specific landing page for agency “Citizens4Us West Java” <https://www.digitalbenefits.uk/ps>
3. Read the web page and click on the link to the Supporters Questionnaire
4. Try completing the questionnaire and submitting it as if you were a supporter, rather than an advisor. You can do this multiple times if you want. Do not submit real personal data.
5. A telephone (or video) interview will be arranged to ask what you like and dislike about the idea, the survey itself, and whether you think it is practical and useful.

Please avoid discussing your own thoughts about this prototype with any other colleagues who are also taking part, until after the interview.

- 3 -

Figure 4: Screen shot of the mock organisation webpage which provides instructions to a claimant's supporter and a link to the online questionnaire

Citizens4Us West Java


PIP: Information from an assistant, carer, helper or supporter

Thank you for coming here. The person who gave you this website address is getting help to claim PIP, and would like to provide as much information to the advisor who will assist them to complete the PIP application form.

Purpose

This is a way to explain what you do for the claimant, so it can be discussed with the advisor and used to help describe how the person's conditions affect their ability to do certain daily activities.

Your information is submitted anonymously. Please do not write anything which identifies either you or the claimant. Use the person's initials and the reference provided on the invitation card, like the example shown below.



Form

The information needed is requested in an online questionnaire which usually takes 5-10 minutes to complete. Thank you for your time — it will really help. There are three ways you can do it. You will need the person's initials and reference from the invitation card.

[Fill in the Supporters Questionnaire by clicking here](#)

If you would prefer a paper form, or would like to print and return a PDF, please contact us.

Please complete the questionnaire as soon as possible, so your helpful information can be discussed during the upcoming form-filling appointment.

Thank you.

Queries or comments

Citizens4Us West Java
c/o Colin Watson
Open Lab
Newcastle University
Urban Sciences Building
Newcastle upon Tyne
NE4 5TG

Figure 5: The initial page of the online questionnaire

PIP Additional Information (v4)

Thank you in advance for completing this form. The information you provide will be used by an advisor to help discuss how the person's conditions affect their ability to do certain daily tasks and the help they receive with those, in order to complete the PIP form as accurately as possible.

Although there are a lot of activities listed, we need to consider all of these to complete a full application. Anything you can identify the person gets help with, will make it easier to focus on what's important.

If you do want to read more about the activities, and what the advisor will discuss with the person claiming, Citizens Advice provide guidance on 'help filling In your PIP claim form' at <https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/PIP/help-with-your-claim/PIP-claim-form/> and the DWP's own "PIP assessment guide part 2" is at <https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/PIP-assessment-guide-part-2-the-assessment-criteria>

Claimant identity and relationship

To enable us to link your response to the person, please provide the initials of the person claiming PIP and the reference provided on the invitation card. Do not write anything which identifies the full name, address, contact details of either yourself, the claimant or any other person.

1. What are the claimant's initials? (if you have an invitation card, their initials are shown on it)
2. What is the reference? (if you have an invitation card, the reference is shown on it)
3. It would help to know whether you are a neighbour, friend, family member, spouse/partner or a professional. How would you describe yourself, and do you visit the person occasionally, or do you live with them, or do you provide remote support such as by telephone? If you help in a professional capacity of some sort, which organisation or individual arranged this?

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Figure 6: Subsequent pages of the questionnaire; one for each PIP assessed activity

16. How often do YOU help the person COMMUNICATE?

Communication means speaking in a way that is understood, listening and understanding in their own native spoken language.

	Always	Often	Sometimes	Never
Communicate on behalf of the person yourself (the person is unable to do this at all)	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Support them to communicate (e.g. help them hear or understand, explain, speak on their behalf, interpret sign language)	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prompt them to communicate (e.g. remind, encourage, motivate)	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>

17. Does the person use any aids/appliances or have any adaptations to help them communicate? If so, what and why?

Enter your answer

18. How often do YOU help the person READ?

Reading is concentrating on and understanding written letters, words, numbers and dates in their own native language, and other instructions such as signs, symbols, notices and timetables, indoors and out.

	Always	Often	Sometimes	Never
Read on behalf of the person yourself (the person is unable to do this at all)	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support them to read (e.g. read, explain)	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Prompt them to read (e.g. remind, encourage, motivate)	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

Figure 7: Optional extra questions

PIP Additional Information (v4) ...

Further details

If you can write some more to expand upon the previous answers, that would be helpful. The information you provide will be discussed at the upcoming form-filling appointment between the advisor and the claimant who you help.

31. Can you describe the help you provide in more detail and if it varies day to day?

32. How long does it take you to provide this help (e.g. one hour every other day)?

33. What happens, or would happen, if YOU don't provide this help?

34. Does the person need other aids or appliances (notes, tools, reminders, equipment, gadgets) or adaptations (changes to their home) which would help, but they do not have or are unable to use? What and why?

35. What other help does the person really need to do these activities fully, properly, and safely - and does anyone else provide this?

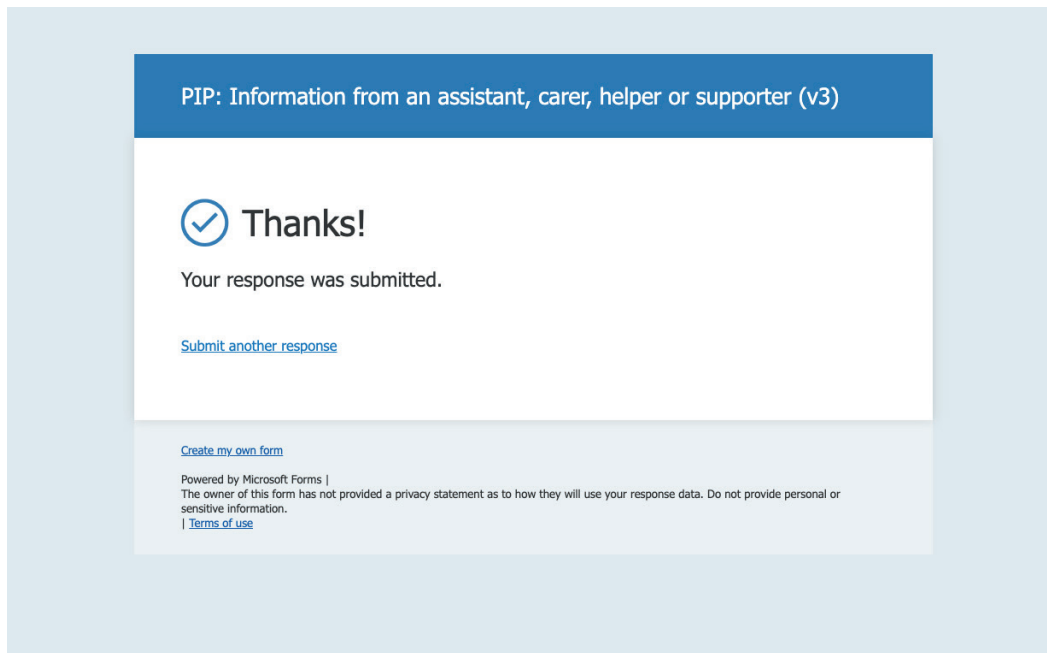
36. Is there any more information you wish to add?
Please let us know if there's anything important that may be missed by the above questions.

[Back](#) [Submit](#)

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Figure 8: The message displayed on submission of the questionnaire



Outcomes from the design and evaluation of the PS Toolkit digital prototype

The digital prototype added to knowledge about how harms arise in the processes for providing evidence to support a PIP claim system and across claimants' support networks. The design of a prototype which alters the system permitted exploration of how harms can alter as the result of changes.

Like the other prototype (*Research Briefing N^o3*), the work validated the categories in the Taxonomy of Harms (*Research Briefing N^o1*) and contributed to new implications for design (*Research Briefing N^o2*). In turn, these helped answer the research questions (*Research Briefing N^o5*). All the research briefings are available as PDFs on the Digital Benefits and Disbenefits (DBD) project website at <https://www.digitalbenefits.uk/>

Subsequent to the research and to help disseminate the findings, a practical tool has been created for those designing and implementing e-government services. DBD Cornucopia helps teams review their work to identify where and how harmful effects can arise, using gamification. Further information and downloads are available at <https://www.digitalbenefits.uk/cornucopia/>

Research Briefing Nº4: PIP Supporters Toolkit

This is one of five documents describing outputs from Colin Watson's doctoral human-computer interaction (HCI) research project *Digital Benefits and Disbenefits*, undertaken 2019–2023 at Open Lab, Newcastle University, UK. These research briefings draw on findings, analysis and discussion published in his thesis *Understanding and Reducing the Negative Effects of Digitisation on Claimants' Access to Online Social Protection Services through the Design of Citizen-Controlled Digital Tools*, supervised by Dr Ahmed Kharrufa (Open Lab, Newcastle University) and Professor Ruth McAreavey (Sociology, Newcastle University). Colin Watson qualified for the award Doctor of Philosophy in the School of Computing on 18 March 2024.

Acknowledgements

The research would not have been possible without the expert knowledge of the participants who were primarily welfare benefit claimants but also others such as those providing advice, support and guidance about welfare benefits. The research was undertaken within Open Lab in the School of Computing at Newcastle University. It was funded by the UK Research and Innovation's Engineering and Physical Sciences Research Council (EPSRC) Centre for Doctoral Training in Digital Civics (EP/L016176/1), exploring how digital technologies can empower citizens and communities, as well as creating real-world impact for the partners they work with.

Imprint

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