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Exploring the mental health effects of Universal Credit: a journey of co-production

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Manuscript Type:	Current Topics & Opinions
Keywords:	Public Health, Inequalities, Mental Health, Universal Credit, co-production, public engagement
Abstract:	

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Manuscripts

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3 Main manuscript for Special Issue of *Perspectives in Public Health*
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5 **Box 1: A poem by (name of public contributor)**
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8 **The Road**
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10 Why does my benefit...CRUSH down.
11

12
13 The road to employed is a steep enough hill, why place a mountain to defeat my
14 will.
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20 The road to good health, is long and hard to chart, why place a minefield to blow
21 me apart.
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44 (Name of public contributor's) poem powerfully illustrates his experiences of
45 Universal Credit. In this paper, we outline our approach to public involvement and
46 engagement (PIE) in a mixed-method, multi-site study about the mental health
47 effects of Universal Credit funded by the National Institute for Health Research
48 (NIHR) (<https://fundingawards.nihr.ac.uk/award/NIHR131709>).
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4 [considering-involvement-in-research/27372](https://www.nihr.ac.uk/documents/payment-guidance-for-members-of-the-public-considering-involvement-in-research/27372). We view public engagement as a social
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12 Engagement in preference to the more commonly used patient and public
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18 and how we meaningfully involve them in the research is evolving over time. Here,
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20 we describe and reflect on the ongoing process of Public Involvement and
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22 Engagement in the context of this four-year research project.
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29 **Background and introduction**

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32 The current study began in May 2021, but the public involvement process started
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38 UC and its consequences for citizens and services. This coincided with (lead author)
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40 working as an embedded researcher in (name of Local Authority) Public Health team
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42 who, in response to these concerns, commissioned qualitative research that
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44 subsequently reported negative experiences of Universal Credit³. Inspired by
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46 powerful narratives of people claiming Universal Credit, including (name of public
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48 contributor), (name of lead author) developed links with (anonymised Voluntary and
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50 Community Sector organisation). Their approach centred on building connections
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52 between people with lived experience and those in positions of power to affect
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54 change. Collaboration between academics with a strong track record of previous
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6 citizens and staff in voluntary organisations and local government informed the
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8 application.
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11 12 13 **Who is involved?** 14

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16 Research team members drew on existing links with stakeholders and Universal
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18 Credit claimants in (anonymised areas of UK) whose knowledge and lived
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20 experience were valued equally. We anticipated claimant's input would benefit the
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22 research in multiple ways: help prioritise the questions we ask in the research,
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24 identify outcomes of interest, and enhance the quality and relevance of the findings.
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26 Although we took a rights-based approach, and were aware of NIHR's emphasis on
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28 paid involvement as a research funder¹⁰, we were (and remain) concerned about the
29
30 practical and personal risks for Universal Credit claimants, including on entitlement,
31
32 eligibility and conditionality. These risks, which we have discussed with colleagues in
33
34 the Department for Work and Pensions (DWP) are outlined in Box 2.
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40 **Box 2: Risks of Public Involvement and Engagement for Universal Credit** 41 **claimants** 42

43 Universal Credit claimants may already be navigating complex Department for
44 Work and Pensions (DWP) rules about payments and conditionality. A principle of
45 conditionality holds that that access to publicly funded welfare benefits, like
46 Universal Credit, should be dependent on an individual agreeing to meet particular
47 obligations¹¹.
48

49 Universal Credit claimants are required to undertake set amounts of work search
50 activities each week. Claimants can face sanctions (where their benefit is stopped
51 temporarily) for perceived breaches of the claimant commitment negotiated with
52 their work coach. Public Involvement and Engagement activity could affect actual
53 or perceived availability for work.
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56 Our previous research showed variability in enforcement/interpretation of Universal
57 Credit rules, resulting in unpredictable decision-making with serious potential
58 consequences for claimants.
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Tensions exist between Universal Credit rules and NIHR requirements to pay public contributors set amounts for public involvement activities. We found it is important to distinguish between vouchers given for participation in research interviews vs reimbursement of expenses vs remuneration for public involvement and engagement activities.

Payments for public involvement activities could count as earned income and could affect Universal Credit entitlement. We advised claimants to seek independent advice about their specific circumstances from welfare rights services.

The perception of claimants' involvement in 'paid work' (Public Involvement and Engagement activities) could threaten their Universal Credit entitlements more broadly, or claimants previously assessed as having 'limited capability for work' could be seen as 'fit for work' following engagement in public involvement activity.

Our approach to Public Involvement and Engagement

We set out our approach to Public Involvement and Engagement in a jointly agreed values statement (see supplementary material 1). We used the Public Involvement Impact Assessment Framework¹² to stimulate discussions about the aims and intended impact of public involvement in each work package. Recognising the need for flexibility, we are working with Universal Credit claimants and stakeholders to explore how they want to be involved and to date have captured these in a menu of options (see practical activities in supplementary material 1). We discussed these with the Department for Work and Pensions and support organisations in efforts to reduce the potential risks of PIE activities. We obtained letters explaining public involvement that UC claimants can use if questioned by Job Centre staff or work coaches. Our budget included payment for public involvement activities according to NIHR guidance. A set of payment options were offered to minimise the risks for Universal Credit claimants who chose to be involved. Guided by advice from Citizens Advice and Department for Work and Pensions, we included options to receive expenses only, or payments to be made to voluntary and community sector (VCS)

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3 organisations (a copy of our public involvement and engagement payment policy is
4 available in supplementary material 2).
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8 Early on, we consulted Universal Credit claimants, advice workers, public
9 involvement leads, and Universal Credit Essentials (UCE; an education and advice
10 charity started and run by current and former UC claimants). Universal Credit
11 Essentials had input during the proposal development process, including
12 commenting on the overall research plan as described in the plain language
13 summary. We simplified qualitative fieldwork documents following advice from public
14 partners and welfare rights colleagues and augmented the written materials with a
15 short film, co-produced with public engagement partners.
16
17

18
19 Our public contributors encouraged us to revise the Privacy Notice, to improve
20 accessibility generally and specifically to ensure clarity on the nature of harms that
21 may require confidentiality to be breached and what action would be taken in that
22 event. The process of ratifying the new version with University colleagues
23 responsible for data protection and ethics seems to have highlighted the value of
24 public engagement and may lead to some changes at an institutional level to ensure
25 the accessibility of public documents. Our discussions with colleagues in finance as
26 a result of public involvement have resulted in changes to claims forms to ensure
27 they are fit for purpose.
28
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31 Our public involvement activities included an opportunity to be involved in the
32 recruitment and selection panel for a new researcher working on the study. Following
33 his involvement, (name of public contributor) offers his thoughts on co-production in
34 box 3 below:
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54 **Box 3: (Name of public contributor's) thoughts on co-production**
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4 After a second relapse of my mental health in 2019, one of the main attributes of
5 my improvement had been my joining the Poverty Truth Commission in
6 (anonymised), as a community or life experience commissioner, relaying my story
7 of my interactions with Universal Credit. This had culminated in a high point when
8 we had our launch event in March 2020.
9

10
11 The offer to take part in co-production of the Universal Credit research project was
12 therapeutic, but also made me feel useful. I haven't worked for 7 years, so the
13 keeping of diaries, attending meetings, helping shape the questionnaire, and being
14 on the recruitment panel for the (anonymised) researcher made me feel my lived
15 experience felt both important and valued, and I felt better in myself.
16
17

18 This has led to feel very strongly on the value of co-production, and the effort it
19 requires to do it properly. Taking information from people who are vulnerable, lack
20 confidence, are suffering mental health, addiction or are of poor education requires
21 patience and empathy but the information received is "pure gold". Only a person
22 living in their situation can give the insight that they bring.
23
24

25 Being part of the recruitment panel allowed me to offer a non-professional, or
26 technical view; was the person warm and nice to speak to, would I want to tell
27 them my story? Did they listen well and understand how they were going to
28 approach this qualitative research and were they open to co-producer's input.
29
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31 32 **How our approach is evolving**

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34 We are at the beginning rather than the end of the journey and anticipate public
35 involvement activities will continue to develop throughout the study, across all
36 workstreams. Public Involvement and Engagement is a standing item at monthly
37 team meetings, and all researchers are encouraged to keep an impact log. One of
38 our aims is to open up the possibilities of public involvement and engagement, and
39 we continue to reflect on our efforts. We are adapting our approach to public
40 involvement and engagement to take account of people's needs and concerns about
41 digital exclusion during COVID. Sometimes this means taking a walk in the park
42 instead of organising an online meeting.
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57 The research team are listening, learning and creating opportunities for others to
58 hear about the effects of Universal Credit through poetry, conversation and continual
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3 dialogue. We are hoping to change assumptions, narratives and perspectives along
4 the way. We remain alert to differences between stated policy and on-the-ground
5 implementation, particularly following conversations with Universal Credit Essentials
6 that Scottish Choices Universal Credit payment arrangements and Alternative
7 Payment Arrangements in the rest of the UK are not markedly different and are often
8 dictated by work coaches at local level.
9

10
11 Our public involvement and engagement payment processes have been in
12 conjunction with public contributors, to establish their preferred methods of payment
13 using guidance about how different kinds of payment will be assessed and taken into
14 account by DWP / Job Centre staff. Colleagues operating university payment and
15 claims systems are open to adapting systems so that they fit the specific
16 requirements of our study public partners. The research team are committed to
17 sharing our learning throughout the study, including developing a publication policy
18 to reflect our learning of co-authoring papers in collaboration with public contributors.
19

20 **Reflections and recommendations for researchers and research funders**

21
22 We are aware that there are limits to the changes that can occur as a result of public
23 involvement and engagement (e.g. study design approved by funders, requirements
24 for inclusion of material on information leaflets.) We aim to be transparent about the
25 limits of influence in the study. Members of the research team built on our previous
26 relationships with practitioners, policy makers and people with experience of
27 Universal Credit. The study benefitted from this early engagement. However,
28 challenges remain in offering meaningful public involvement and engagement
29 opportunities *before* formal research funding begins. Pump priming funding for
30 researchers to have capacity to start these processes before an application/award
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3 begins would be beneficial. Time is needed for meaningful co-production to be
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5 factored in to research designs. Our experience has demonstrated the immense
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7 contributions of voluntary and community organisations that provide support for
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9 people involved in research.
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13 Working together on a Public Involvement and Engagement Values Framework
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15 helped build trust and shared understanding between team members, stakeholders
16
17 and public contributors. Anticipating potential risks of harm added layers of
18
19 complexity¹³. Paying close attention early on to remuneration issues helped reduce
20
21 potential adverse impact on Universal Credit claimants. We remain concerned that,
22
23 depending on Universal Credit claimants' circumstances, NIHR recommend payment
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25 rates could cause significant harm to some of the people we most want to engage in
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27 research. For this reason, we remain vigilant about the potential costs to public
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29 partners¹⁴. and seek ways to reduce the possibility of involvement exacerbating /
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31 widening existing health inequalities
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37 Public involvement enhanced the researcher recruitment and selection process in
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39 this study and should become routine practice in university appointments for publicly
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41 funded research. We acknowledge the structural difficulties of sharing power in the
42
43 context of existing research hierarchy within which co-production commonly takes
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45 place¹⁵. Our experience has shown that public involvement and engagement can
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47 disrupt taken for granted assumptions, values and norms if people are open to
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49 change and differing perspectives. Capturing these outside our multi-disciplinary
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51 research team is not straightforward¹⁶.
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Conclusions

Undertaking research on Universal Credit requires a focus on the perspectives of communities most at-risk². None of the research team members consider themselves experts in public involvement or co-production. Our approach has been characterised by humility and a willingness to try new approaches, build new relationships, listen and learn from experience. Public Involvement and Engagement is firmly established in our ongoing research, which enables regular reflection as well as acknowledging and addressing the possibilities of unintended consequences. We anticipate more bumps in the road. Whilst hopeful we may have contributed by outlining our approach, we are aware that the existing 'hierarchies of academic knowledge production'¹⁶ make it challenging to fully realise the transformative potential of publicly engaged research.

[2332 words including text in boxes]

Declaration of competing interests

The authors declare no conflicts of interest.

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The perception of claimants' involvement in 'paid work' (Public Involvement and Engagement activities) could threaten their Universal Credit entitlements more broadly, or claimants previously assessed as having 'limited capability for work' could be seen as 'fit for work' following engagement in PIE-public involvement activity.

Our approach to Public Involvement and Engagement

We set out our approach to Public Involvement and Engagement in a jointly agreed values statement (see supplementary material 1). We used the Public Involvement Impact Assessment Framework¹² to stimulate discussions about the aims and intended impact of public involvement in each work package. Recognising the need for flexibility, we are working with Universal Credit claimants and stakeholders to explore how they want to be involved and to date have captured these in a menu of options (see practical activities in supplementary material 1). We discussed these with the Department for Work and Pensions and support organisations in efforts to reduce the potential risks of PIE activities. We obtained letters explaining public involvement PIE that UC claimants can use if questioned by DWP-Job Centre staff or work coaches. Our budget included payment for PIE-public involvement activities according to NIHR guidance. A set of payment options were offered to minimise the risks for Universal Credit claimants who chose to be involved. Guided by advice from Citizens Advice and Department for Work and Pensions, we included options to receive expenses only, or payments to be made to voluntary and community sector

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3 (VCS) organisations (a copy of our [PIE-public involvement and engagement](#)
4 payment policy is available in supplementary material 2).
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8 Early on, we consulted [Universal Credit](#) claimants, advice workers, public
9 involvement leads, and Universal Credit Essentials (UCE; an education and advice
10 charity started and run by current and former UC claimants). [Universal Credit](#)
11 [Essentials](#) had input during the proposal development process, including
12 commenting on the overall research plan as described in the plain language
13 summary. We simplified qualitative fieldwork documents following advice from [public](#)
14 [partners and PIE-welfare rights](#) colleagues and augmented the written materials with
15 a short film, co-produced with public engagement partners.
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27 Our public contributors encouraged us to revise the Privacy Notice, to improve
28 accessibility generally and specifically to ensure clarity on the nature of harms that
29 may require confidentiality to be breached and what action would be taken in that
30 event. The process of ratifying the new version with University colleagues
31 responsible for data protection and ethics seems to have highlighted the value of
32 public engagement and may lead to some changes at an institutional level to ensure
33 the accessibility of public documents. Our discussions with colleagues in finance as
34 a result of [PIE-public involvement](#) have resulted in changes to claims forms to
35 ensure they are fit for purpose.
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48 Our [PIE-public involvement](#) activities included an opportunity to be involved in the
49 recruitment and selection panel for a new researcher working on the study. Following
50 his involvement, (name of public contributor) offers his thoughts on co-production in
51 box 3 below:
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Box 3: (Name of public contributor's) thoughts on co-production

After a second relapse of my mental health in 2019, one of the main attributes of my improvement had been my joining the Poverty Truth Commission in (anonymised), as a community or life experience commissioner, relaying my story of my interactions with Universal Credit. This had culminated in a high point when we had our launch event in March 2020.

The offer to take part in co-production of the [Universal Credit](#) research project was therapeutic, but also made me feel useful. I haven't worked for 7 years, so the keeping of diaries, attending meetings, helping shape the questionnaire, and being on the recruitment panel for the (anonymised) researcher made me feel my lived experience felt both important and valued, and I felt better in myself.

This has led to feel very strongly on the value of co-production, and the effort it requires to do it properly. Taking information from people who are vulnerable, lack confidence, are suffering mental health, addiction or are of poor education requires patience and empathy but the information received is "pure gold". Only a person living in their situation can give the insight that they bring.

Being part of the recruitment panel allowed me to offer a non-professional, or technical view; was the person warm and nice to speak to, would I want to tell them my story? Did they listen well and understand how they were going to approach this qualitative research and were they open to co-producer's input.

How our approach is evolving

We are at the beginning rather than the end of the journey and anticipate [PIE public involvement](#) activities will continue to develop throughout the study, across all workstreams. [Public Involvement and Engagement](#) is a standing item at monthly team meetings, and all researchers are encouraged to keep an [impact-PIE](#) log. One of our aims is to open up the possibilities of [PIE public involvement and engagement](#), and we continue to reflect on our efforts. ~~To date w~~We are: ~~A~~adapting our approach to [PIE public involvement and engagement](#) to take account of people's needs and concerns about digital exclusion during COVID. Sometimes this means taking a walk in the park instead of organising an online meeting.

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2
3 The research team are Listening, learning and creating opportunities for others to
4 hear about the effects of Universal Credit through poetry, conversation and continual
5 dialogue. We are, hoping to change assumptions, narratives and perspectives along
6 the way. We Rremaining alert to differences between stated policy and on-the-
7 ground implementation, particularly following conversations with Universal Credit
8 Essentials that Scottish Choices Universal Credit payment arrangements and
9 Alternative Payment Arrangements in the rest of the UK are not markedly different
10 and are often dictated by work coaches at local level.

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22 - Developing Our public involvement and engagement payment processes
23 have been in conjunction with PIE public contributors, to establish their preferred
24 methods of payment using guidance about how different kinds of payment will be
25 assessed and taken into account by DWP / Job eCentre staff. Finding eColleagues
26 operating university payment and claims systems are open to adapting systems so
27 that they fit the specific requirements of our study PIE-public partners. The research
28 team are committed to Ssharing our learning throughout the study, including
29 developing a publication policy to reflect our learning of co-authoring papers in
30 collaboration with public contributors.
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43 **Reflections and recommendations for researchers and research funders**

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47 ●—— We are aware that there are limits to the changes that can occur as a result of
48 public involvement and engagement PIE (e.g. study design approved by funders,
49 requirements for inclusion of material on information leaflets.) We aim to be
50 transparent about the limits of influence in the study.
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56 ●—— WeMembers of the research team built on our previous relationships with
57 practitioners, policy makers and people with experience of Universal Credit. The
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3 study benefitted from this early engagement. However, challenges remain in offering
4 meaningful PIE-public involvement and engagement opportunities *before* formal
5
6 research funding begins.
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11 ●—— Pump priming funding for researchers to have capacity to start these
12 processes before an application/award begins would be beneficial.
13

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16 ●—— Time is needed for meaningful co-production ~~which needs~~ to be factored in to
17 research designs.
18

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21 ● Our experience has demonstrated ~~We recognise~~ the immense contributions of
22 voluntary and community organisations that provide support for people involved in
23 research.
24

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27 ●—— Working together on a PIE Public Involvement and Engagement Values
28 Framework helped build trust and shared understanding between team members,
29 stakeholders and public contributors. Anticipating potential risks of harm added
30 layers of complexity¹³.
31

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34 ●—— Paying close attention early on to remuneration issues helped reduce
35 potential adverse impact on Universal Credit claimants. ~~Anticipating potential risks of~~
36 ~~harm added layers of complexity~~¹³. We remain concerned that,
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40 ●—— ~~D~~depending on Universal Credit claimants' circumstances, NIHR recommend
41 payment rates could cause significant harm to some of the people we most want to
42 engage in research. For this reason,
43

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46 ● We remain vigilant about the potential costs to public partners¹⁴. and seek
47 ways to reduce the possibility of involvement exacerbating / widening existing health
48 inequalities
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3 ● Public involvement enhanced the researcher recruitment and selection
4 process in this study and should .~~We suggest this~~ becomes routine practice in
5
6 university appointments for publicly funded research. W
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11 ● We acknowledge the structural difficulties of sharing power in the context of
12 existing research hierarchy within which co-production commonly takes place¹⁵.
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16 ● ~~PIE~~ Our experience has shown that public involvement and engagement can
17 disrupt taken for granted assumptions, values and norms if people are open to
18 change and differing perspectives. Capturing these outside our multi-disciplinary
19 research team is not straightforward¹⁶.
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28 **Conclusions**

29
30 Undertaking research on Universal Credit requires a focus on the perspectives of
31 communities most at-risk ². None of the research team members consider
32 themselves experts in public involvement or co-production. Our approach has been
33 characterised by humility and a willingness to try new approaches, build new
34 relationships, listen and learn from experience. Public Involvement and Engagement
35 is firmly established in our ongoing research, which enables regular reflection as well
36 as acknowledging and addressing the possibilities of unintended consequences. We
37 anticipate more bumps in the road. Whilst hopeful we may have contributed by
38 outlining our approach, we are aware that the existing 'hierarchies of academic
39 knowledge production'¹⁶ make it challenging to fully realise the transformative
40 potential of publicly engaged research.
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58 [2198-2332 words including text in boxes]
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Declaration of competing interests

The authors declare no conflicts of interest.

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Supplementary material 2

Evaluation of the health impacts of Universal Credit (NIHR131709)

Public Involvement and Engagement (PIE) Values Framework

The overall aims of public involvement and engagement (PIE) in this study are to ensure:

- The research addresses the primary questions of interest for the public, claimants and their advocates, policy makers and practitioners
- Public members have meaningful opportunities to guide and inform the research process
- Data analysis makes sense
- Findings are presented in ways that are accessible for target audiences.

Who are public members for this study?

People with experience of claiming Universal Credit (UC), policy makers and practitioners with working knowledge of UC implementation.

Our approach to Public Involvement and Engagement

The research team will build on and maintain working relationships with organisations and networks supporting UC claimants and other stakeholders through regular communication. Formal and informal opportunities for involvement and engagement will be offered through existing partnerships in the North East and North West of England and West of Scotland.

The research team will seek active input of those with experience of claiming UC, policy makers and practitioners with working knowledge of UC implementation to:

- Provide timely insights about how any changes to UC policy play out in practice.
- Advise on feasibility of research methods, provide a sounding board for researchers to test ideas as each work package (WP) progresses.
- Consider potential positive and negative consequences of the implementation of UC on claimants and their families.
- Contribute knowledge and understanding of the policy levers, mediating mechanisms and equity characteristics that are important in UC.
- Guide researchers to ensure inclusion of people who may be affected by the introduction of UC.
- Ensure diverse views are sought, including members of groups adversely affected by health and social inequalities.
- Provide links with wider networks.

Practical activities may include the following:

- Shape and refine the logic model for the study.
- Review the values framework developed to inform public involvement and engagement (PIE).
- Inform the development of ethics applications and supporting documents.
- Contribute to the recruitment and selection process of researchers working on the study.
- Contribute to the development of research materials, including Participant Information Sheets, consent forms, topic guides and other documentation for WP3.
- Facilitate, guide and support sampling and recruitment of research participants and suggest practical solutions to issues encountered by the team.
- Contribute to data analysis and sense checking of early findings.
- Co-author publications and jointly present at conferences and events.
- Build support and capacity among UC claimants to undertake their own independent research

Our approach is informed by the [NENC ARC \(2021\) strategy for public involvement and engagement](#), and evidence of what works in developing and maintaining effective public involvement. The research team will support members of the public to contribute to the research through a range of activities to optimise the relevance, implementation and dissemination of research. Regular opportunities for PIE will be provided online and, where possible, through PIE meetings in each study locality. The research team see these interactions as vital to the effective conduct of the study.

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2
3
4 Subject to COVID restrictions, the format and frequency of face-to-face meetings will be negotiated
5 with public members, who will be reimbursed for their contribution according to [NIHR guidance](#)
6 [\(2021\)](#), avoiding any potentially adverse effects on UC entitlement or eligibility.
7

8 We will provide UC claimants with a letter for DWP / their Work Coach as recommended in the NIHR
9 guidance (2021). We recognise that a donation directly to a group or support organisation may be
10 preferable, offering control over how the money is used without affecting individual's benefit
11 entitlement or eligibility. In the event of any difficulties/adverse impact on any individual case, this will
12 be taken up with the NIHR Benefits helpline if necessary.
13

14 The research team have co-developed the values framework underpinning their approach to PIE,
15 using the Public Involvement Impact Assessment Framework (Piiaf) (Popay and Collins 2014)
16 <https://piiaf.org.uk/documents/values-summary.pdf>. This has been discussed and agreed by all
17 research team members.
18

19 By the start of fieldwork, we will have worked through the questions in the Public Involvement Impact
20 Assessment Framework (<http://piiaf.org.uk/documents/exec-summary-0114.pdf>) agreed the PIE
21 methods the team will use, identified potential barriers and facilitators, and negotiated practical issues
22 re. funding, remuneration and reimbursement with University finance departments. A payment policy
23 has been drafted and agreed by stakeholders.
24

25 We will agree a consistent approach to recording our PIE activities, including any unintended
26 consequences, piloting the use of PIE Impact logs and the GRIPP2 short form available here
27 <https://www.bmj.com/content/358/bmj.j3453>. This will be reviewed after 3 months.
28

29 **Values Framework**

30 The research team believe:

- 31 • Effective PIE is of intrinsic value. It is a fundamental human right to have a say, and for public
32 views to be heard and taken into account in the conduct of research.
- 33 • UC claimants and staff supporting them have a right to be involved in meaningful
34 opportunities to shape the research to ensure its relevance
35

36
37 The research team will:

- 38 • Allocate sufficient time for meaningful public involvement throughout the research process
- 39 • Communicate clearly from the outset with members of the public
- 40 • Respect public contributors' rights to confidentiality
- 41 • Take account of the views of public members in the conduct of the research
- 42 • Respect the diversity of values, skills, knowledge and experience people bring
- 43 • Value, acknowledge and reward public involvement.
- 44 • Negotiate reimbursement for expenses and costs of taking part, to ensure individuals are not
45 out of pocket, in collaboration with UC claimants and staff supporting them, respecting
46 individual wishes and circumstances
- 47 • Seek ways to involve UC claimants and staff supporting them in ways which minimise the
48 risks of harm for those who chose to be involved.
- 49 • Explain potential risks of PIE including financial harm, eligibility or entitlement to UC, health
50 and wellbeing of public contributors
- 51 • Aim to resolve disagreements or differences of opinion in open, honest, transparent ways
- 52 • Host research activities, and provide opportunities to contribute to joint analysis,
53 interpretation of findings and development of recommendations to ensure they make sense
- 54 • Seek public involvement in dissemination strategies to ensure they are accessible for diverse
55 target audiences
- 56 • Ensure that involvement is not overly burdensome for PIE partners
- 57 • Enable public contributors to stop their involvement at any point without giving reasons
58
59
60

- Communicate and keep records of changes made in response to PIE activities
- Seek feedback about the experience of PIE in this study, including any unintended or adverse consequences, and take steps to mitigate future risks
- Adhere to the NIHR policy on preventing harm in research in undertaking PIE activities
<https://www.nihr.ac.uk/documents/nihr-policy-on-preventing-harm-in-research/27567>

Researchers, academics, policy and practice partners involved in the Advisory Group and Study Steering Committee will be encouraged to use the values framework to inform and review the involvement and engagement activities undertaken as part of the study.

References

ESRC Framework for Research Ethics (<https://esrc.ukri.org>)

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Supplementary material 2

NIHR Universal Credit Study Public Involvement and Engagement (PIE) Payment Policy

<https://fundingawards.nihr.ac.uk/award/NIHR131709>

As set out in the NIHR guidance on payment <https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392>, the Universal Credit study team are committed to having a clear policy on payment and recognition in place prior to involvement, so that members of the public know in advance what is being offered and are able to make informed decisions about getting involved.

The research team aims to provide clear and consistent information to members of the public involved in the NIHR funded study on Universal Credit about what to expect before, during and after public involvement. This document includes the processes for members of the public involved in the Universal Credit study to claim payment and expenses.

This policy has been developed with the involvement and agreement of Glasgow University and Northumbria University finance, payroll and HR departments to ensure it can be implemented using existing systems.

The research team have sought advice from the Department for Work and Pensions (DWP), from members of the public who are UC claimants and from staff supporting them, including an expert welfare benefits adviser, on the conditions that must be followed by members of the public who are in receipt of state benefits, including Universal Credit.

The research team have included measures to alleviate potential benefit barriers and to prevent misunderstandings with Jobcentres that may lead to benefits being stopped or reviewed. A letter can be provided for UC claimants involved in the study to show their Work Coach.

This letter states that good practice guidance for service user involvement in research recommends that members of the public should be offered payment for activities such as attending meetings and events, and that reasonable out-of-pocket expenses should be covered. It notes that:

- as involvement activities are often arranged on an ad hoc basis, organisations often pay service users monthly in arrears
- to assist service users who receive welfare benefits which have earnings limits or disregards, organisations offer involvement on a voluntary basis, or at a lesser amount, if requested
- as the payment period may be over a month or more, we anticipate that Jobcentre Plus will treat these payments as averaged over the payment period. (See DMG Chapter 48 paras 4080-81 and for a cycle of work para 48094).
- the Department for Work and Pensions legislation exempts 'service users and carers' from the application of notional earnings and treats reimbursed expenses for service user involvement as ignored (see ADM Chapter H3, paras 3160 and 3241)
- service users can withdraw from involvement activities at any time to attend 'employment-related' activities

1
2
3 The PIE payment policy for the evaluation of the health impacts of Universal Credit study will
4 adopt the payment rates suggested by NIHR in their payment [guidance](#). The amounts
5 offered vary according to activities undertaken. Examples of payment rates for involvement
6 activities members of the public should expect to be offered for each activity have been
7 categorised and the payment rates allocated to these are set out [here](#).

8
9 The research team will offer members of the public the option of asking for payment at a
10 lower amount or declining a payment and offering to volunteer or offering payment to a
11 specific charity or voluntary organisation of their choice.

12
13 The Public Involvement and Engagement Values Framework developed for the study
14 provides information about the nature of the involvement opportunities available. The
15 research team will negotiate the nature, duration and frequency of involvement with
16 members of the public involved and will ensure that expenses are covered so no-one is out
17 of pocket as a result of their involvement.

18
19 The expenses which can be reimbursed or covered according to standard organisational
20 policy include:

- 21 • Mileage allowance according to current [HMRC guidance](#)
- 22 • Travel, transport and subsistence rates according to [HMRC guidance](#)
- 23 • Travel expenses, taxi, childcare, carer, personal assistant costs may be paid for in
24 advance where necessary.

25
26 The process of claiming payments and expenses is set out here. With agreement by relevant
27 research team / work package lead, members of the public will be asked to complete a
28 Northumbria University claim for involvement form (available on request from the study PIE
29 lead Mandy Cheetham).

30
31 Options for rewarding involvement will be agreed as follows and the relevant sections of the
32 form completed and returned to Mandy.Cheetham@Northumbria.ac.uk for processing:

- 33 • Hourly rate of pay processed via the University payroll system (using NIHR rates)
- 34 • Voluntary, no payment required.
- 35 • Payment to another nominated organisation.
- 36 • Out of pocket expenses only.

37
38 If members of the public opt for payment via payroll, we have been advised that they may be
39 asked for evidence of right to work in the UK to be verified by the University.

40
41 The cut-off dates for organisational systems, mean that forms need to be submitted by the
42 5th of the month to ensure payment will be received the following month.

43
44 Members of the public who receive benefits, including Universal Credit will be advised that
45 different benefit conditions and payment limits or disregards exist depending on their
46 particular sets of circumstances.

47
48 The research team will advise a person who is registered self-employed that they will be
49 responsible for their own tax. UC claimants will be advised about sources of personalised
50 advice (see below).

51
52 Welfare Rights Advice for individuals can be obtained free from local Citizens Advice
53 services

54
55 Citizens Advice National Advice line England Tel. 0800 144 8848 Monday – Friday 9am-5pm

1
2
3 Citizens Advice National Advice Line Scotland Tel. 0800 028 1456 Monday – Friday 9am-
4 5pm
5

6 or by contacting mandy.cheetham@northumbria.ac.uk from the research team who can
7 request a ticket number for the Welfare Rights Service at Citizens Advice Bedford Tel. 01234
8 867944. A phone appointment can then be arranged individually or with support from the
9 research team.
10

11 A tailored letter from the research team will be provided on request for UC claimants who are
12 involved in PIE to prevent misunderstandings with Jobcentre Plus staff. The letter will:
13

- 14 • explain how involvement is different to employment and about support for mobility or
15 care needs
- 16
- 17 • allow members of the public who receive state benefits sufficient time to obtain
18 reliable advice on their benefit conditions and to consider what level of involvement
19 and payment they can accept, and sufficient time to follow required Jobcentre Plus
20 procedures
21

22 The PI and research team members will regularly review the PIE payment policy to:
23

- 24 • ensure that staff who administer the policy have relevant training and ongoing
25 support
- 26
- 27 • the policy is updated regularly to ensure that it remains relevant
- 28
- 29 • ensure any problems are resolved promptly and efficiently
30

31 We aim to write in clear plain language, and welcome feedback if we have not achieved this,
32 or if other formats are required.
33

34 We will adhere to the NIHR policy on preventing harm in research in undertaking PIE
35 activities [https://www.nihr.ac.uk/documents/nihr-policy-on-preventing-harm-in-](https://www.nihr.ac.uk/documents/nihr-policy-on-preventing-harm-in-research/27567)
36 [research/27567](https://www.nihr.ac.uk/documents/nihr-policy-on-preventing-harm-in-research/27567).
37

38 Mandy Cheetham (PIE lead) or Peter Craig (Principle Investigator) can be contacted if there
39 is a problem with payment or expenses for the study.
40

41 Contact details

42 Mandy.cheetham@northumbria.ac.uk

43 Peter.Craig@glasgow.ac.uk
44
45
46
47

48 Further information about DWP guidance is available here

49 DWP decision makers guidance [Advice for decision making: staff guide - GOV.UK](https://www.gov.uk/guidance/advice-for-decision-making-staff-guide)
50 www.gov.uk
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56 Draft 2.

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58 Review date January 2022.
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