

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

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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.  
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13 The road to employed is a steep enough hill, why place a mountain to defeat my  
14 will.  
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17 Why does my benefit...CRUSH down.  
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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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8 the core value of social justice, shaped by wider societal developments towards  
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10 realizing citizen empowerment<sup>2</sup>. We adopted the term Public Involvement and  
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12 Engagement in preference to the more commonly used patient and public  
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16 Universal Credit and staff supporting them. Deciding who our relevant 'publics' are,  
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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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34 long before in 2016 in North East England when the public, voluntary sector staff and  
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36 elected members in local government began voicing concerns about the rollout of  
37  
38 UC and its consequences for citizens and services. This coincided with (lead author)  
39  
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  
43  
44 subsequently reported negative experiences of Universal Credit<sup>3</sup>. Inspired by  
45  
46 powerful narratives of people claiming Universal Credit, including (name of public  
47  
48 contributor), (name of lead author) developed links with (anonymised Voluntary and  
49  
50 Community Sector organisation). Their approach centred on building connections  
51  
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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56 work highlighting the health impacts of UK welfare reforms over the last decade<sup>4 5 6 7</sup>  
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4  
5 welfare system (19/106). Longstanding partnerships between the research team,  
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7 citizens and staff in voluntary organisations and local government informed the  
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9 application.  
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### 12 13 **Who is involved?**

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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  
19  
20 experience were valued equally. We anticipated claimant's input would benefit the  
21  
22 research in multiple ways: help prioritise the questions we ask in the research,  
23  
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  
27  
28 paid involvement as a research funder<sup>10</sup>, we were (and remain) concerned about the  
29  
30 practical and personal risks for Universal Credit claimants, including on entitlement,  
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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**

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43 Universal Credit claimants may already be navigating complex Department for  
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45 Work and Pensions (DWP) rules about payments and conditionality. A principle of  
46  
47 conditionality holds that that access to publicly funded welfare benefits, like  
48  
49 Universal Credit, should be dependent on an individual agreeing to meet particular  
50  
51 obligations<sup>11</sup>.

52  
53 Universal Credit claimants are required to undertake set amounts of work search  
54  
55 activities each week. Claimants can face sanctions (where their benefit is stopped  
56  
57 temporarily) for perceived breaches of the claimant commitment negotiated with  
58  
59 their work coach. Public Involvement and Engagement activity could affect actual  
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or perceived availability for work.

Our previous research showed variability in enforcement/interpretation of Universal  
Credit rules, resulting in unpredictable decision-making with serious potential  
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 Framework<sup>12</sup> 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.  
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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.  
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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.  
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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.  
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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.  
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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.  
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### 31 32 33 **How our approach is evolving**

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35 We are at the beginning rather than the end of the journey and anticipate public  
36 involvement activities will continue to develop throughout the study, across all  
37 workstreams. Public Involvement and Engagement is a standing item at monthly  
38 team meetings, and all researchers are encouraged to keep an impact log. One of  
39 our aims is to open up the possibilities of public involvement and engagement, and  
40 we continue to reflect on our efforts. We are adapting our approach to public  
41 involvement and engagement to take account of people's needs and concerns about  
42 digital exclusion during COVID. Sometimes this means taking a walk in the park  
43 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  
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5 the way. We remain alert to differences between stated policy and on-the-ground  
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7 implementation, particularly following conversations with Universal Credit Essentials  
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9 that Scottish Choices Universal Credit payment arrangements and Alternative  
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11 Payment Arrangements in the rest of the UK are not markedly different and are often  
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13 dictated by work coaches at local level.  
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17 Our public involvement and engagement payment processes have been in  
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19 conjunction with public contributors, to establish their preferred methods of payment  
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21 using guidance about how different kinds of payment will be assessed and taken into  
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23 account by DWP / Job Centre staff. Colleagues operating university payment and  
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25 claims systems are open to adapting systems so that they fit the specific  
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27 requirements of our study public partners. The research team are committed to  
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29 sharing our learning throughout the study, including developing a publication policy  
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31 to reflect our learning of co-authoring papers in collaboration with public contributors.  
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### 34 35 36 **Reflections and recommendations for researchers and research funders**

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38 We are aware that there are limits to the changes that can occur as a result of public  
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40 involvement and engagement (e.g. study design approved by funders, requirements  
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42 for inclusion of material on information leaflets.) We aim to be transparent about the  
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44 limits of influence in the study. Members of the research team built on our previous  
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46 relationships with practitioners, policy makers and people with experience of  
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48 Universal Credit. The study benefitted from this early engagement. However,  
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50 challenges remain in offering meaningful public involvement and engagement  
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52 opportunities *before* formal research funding begins. Pump priming funding for  
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54 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  
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17 and public contributors. Anticipating potential risks of harm added layers of  
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19 complexity<sup>13</sup>. Paying close attention early on to remuneration issues helped reduce  
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21 potential adverse impact on Universal Credit claimants. We remain concerned that,  
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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 partners<sup>14</sup>. 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  
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43 context of existing research hierarchy within which co-production commonly takes  
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45 place<sup>15</sup>. 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 straightforward<sup>16</sup>.  
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## Conclusions

Undertaking research on Universal Credit requires a focus on the perspectives of communities most at-risk<sup>2</sup>. 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'<sup>16</sup> 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 current study began in May 2021, but the **Public Involvement and Engagement** process started long before in 2016 in North East England when the public, voluntary sector staff and elected members in local government began voicing concerns about the rollout of UC and its consequences for citizens and services. This coincided with (lead author) working as an embedded researcher in (name of **Local Authority**) Public Health team who, in response to these concerns, commissioned qualitative research that subsequently reported negative experiences of **Universal Credit**<sup>3</sup>. Inspired by powerful narratives of people claiming **Universal Credit**, including (name of public contributor), (name of lead author) developed links with (anonymised **Voluntary and Community Sector** organisation). Their approach centred on building connections between people with lived experience and those in positions of power to affect change. Collaboration between academics with a strong track record of previous work highlighting the health impacts of UK welfare reforms over the last decade<sup>4 5 6 7</sup>

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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  
45 Work and Pensions (DWP) rules about UC-payments and conditionality. A  
46  
47 principle of conditionality holds that that access to publicly funded welfare benefits,  
48  
49 like Universal Credit, should be dependent on an individual agreeing to meet  
50  
51 particular obligations<sup>11</sup>.

52  
53 Universal Credit claimants are required to undertake set amounts of work search  
54  
55 activities each week. Claimants can face sanctions (where their UC-benefit is  
56  
57 stopped temporarily) for perceived breaches of the claimant commitment  
58  
59 negotiated with their work coach. Public Involvement and Engagement activity  
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could affect actual or perceived availability for work.

Our previous research showed variability in enforcement/interpretation of Universal  
Credit rules, resulting in unpredictable decision-making with serious potential  
consequences for claimants.

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Tensions exist between [Universal Credit](#) rules and NIHR requirements to pay public contributors set amounts for [PIE-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 [PIE-public involvement and engagement](#) activities.

Payments for [PIE-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 [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 Framework<sup>12</sup> 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: Aadapting 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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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  
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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.  
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16 ●—— Time is needed for meaningful co-production ~~which needs~~ to be factored in to  
17 research designs.  
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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.  
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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 complexity<sup>13</sup>.  
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~~<sup>13</sup>. 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,  
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46 ● We remain vigilant about the potential costs to public partners<sup>14</sup>. 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 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 place<sup>15</sup>.  
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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 straightforward<sup>16</sup>.  
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## 28 **Conclusions**

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30 Undertaking research on Universal Credit requires a focus on the perspectives of  
31 communities most at-risk <sup>2</sup>. 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'<sup>16</sup> make it challenging to fully realise the transformative  
40 potential of publicly engaged research.  
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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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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  
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- 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

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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 5<sup>th</sup> 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](mailto: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-  
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](mailto:Mandy.cheetham@northumbria.ac.uk)

43 [Peter.Craig@glasgow.ac.uk](mailto: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  
50 \(www.gov.uk\)](https://www.gov.uk/guidance/advice-for-decision-making-staff-guide)  
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55

56 Draft 2.

57  
58 Review date January 2022.  
59  
60