

INFORMATION SHEET

Payment for public involvement with INVOLVE for those in receipt of welfare benefits

Updated: November 2018

How to use this information sheet

This information may be helpful if you are in receipt of welfare benefits and are considering paid involvement with the INVOLVE Coordinating Centre.

The sheet is in two parts:

Part One – has information for you about what to consider when offered paid involvement with INVOLVE. This includes where to seek expert advice about how payment may affect any welfare benefits that you receive, and suggests what to do once you have received that advice.

Part Two – may be shared with Jobcentre Plus staff when corresponding or discussing payment for involvement, and may be enclosed with a Permitted Work (PW1) form, if you require approval before taking on paid involvement.

This sheet includes a description of INVOLVE and the purpose of involvement. It explains the context in which payment is offered and how public involvement in research is different from paid employment (especially important to those receiving benefits for limited capacity for work). The sheet also explains that you can withdraw from public involvement activities at any time (important to those participating in a 'work programme' or actively seeking work).

Part Two of this sheet also refers to sections of the Department for Work and Pensions staff guidance that addresses the regulations covering payment for 'service user involvement'.



PART ONE

For many INVOLVE activities, payment for your time while involved will be offered to show our appreciation for you sharing your knowledge, experience and perspectives on health and social care issues. Any payment that is offered will be in line with the INVOLVE Coordinating Centre's [policy](#) on payment, reward and recognition.

Before you accept an offer to become involved in paid activities, you should seek advice about how payment might affect any welfare benefits that you receive.

Some welfare benefits have conditions that limit the earnings you can accept, and require you to ask permission from the benefits authorities before starting involvement. Other benefits require you to notify earnings. In some circumstances, payment received without permission can lead to welfare benefits being reduced or stopped.

To avoid misunderstandings, INVOLVE recommends that you take advice from the [Benefits Advice Service](#), which provides free, confidential and personalised guidance on how payment for involvement might affect any welfare benefits that you receive. This specialist service is provided by the Bedford Citizens Advice Bureau (see attached leaflet).



Once you have taken advice, and fulfilled any requirements of the benefits authorities, please let us know what payment you wish to accept. INVOLVE's payments policy is flexible, allowing us to offer lesser amounts, or voluntary status, if this is your preference.

This information sheet is offered to all members of the public engaged in paid activities with INVOLVE, as individual's circumstances may change during the period of involvement.

If you require further copies of this information sheet, please contact a member of staff at the INVOLVE Coordinating Centre: 02380 595628 or at involve@nihr.ac.uk.

PART TWO

This information sheet may help to clarify the purpose and context of any payment you may receive from INVOLVE for public involvement activities. This sheet may be shared with benefits authority staff (such as Jobcentre Plus staff) when declaring the payment. It refers to Department for Work and Pensions' regulations about service user involvement in the staff guide, Advice for Decision Makers (ADM) Chapter V4.

INVOLVE

INVOLVE is part of, and funded by, the National Institute for Health Research to support active public involvement in NHS, public health and social care research. As a national advisory group our role is to advance public involvement in all stages of research, including how research is identified, prioritised, designed, conducted and disseminated.

INVOLVE invites members of the public to become involved in our activities to offer a service user perspective because of their personal experience of health and / or social care research and services (*for a definition of service users, see ADM Chapter V4, para 4120*).

The difference between service user involvement and work

Involvement in our activities should not be mistaken as capacity for work, and recruitment for service user involvement should not be confused with recruitment for employment.

INVOLVE's activities that include members of the public:

- are intermittent and people can withdraw at any time
- vary in length and in frequency, and usually last for a few hours (or less) in any one week
- are individual activities and do not imply future involvement
- may include attendance of quarterly or annual meetings
- may include contributing to intermittent meetings or telephone conferences
- may include helping to prepare for meetings, telephone conferences or events
- may include some follow-up activities after meetings or events

Any payment that is offered for service user involvement is intended to cover preparation, attendance and appropriate follow-up activities.

Support provided

INVOLVE provides support measures that are appropriate for each individual, so that members of the public can attend and contribute to our meetings and events. Involvement in INVOLVE activities should not be interpreted as a reduction in the care or mobility needs of service users involved.

Support is offered as required by the service user and may cover preparation, travel to and from a venue, and contributions both during and after the activity. For example, support may include provision of childcare, or provision of a personal assistant or a support worker, to enable the individual to most effectively contribute to the activity.

Payment for service user involvement at INVOLVE

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. Please note that:

- as INVOLVE activities are often arranged on an ad hoc basis, we pay service users in arrears for each activity
- to assist service users whose welfare benefits have earnings limits or disregards, INVOLVE will 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 (*for information on employers' pay arrangements, see ADM Chapter V4, para 4792; for information on averaging over a period of a month or three months, see ADM Chapter V4, paras 4800 and 4801*)
- 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 V4, para 4119*)
- service users can withdraw from INVOLVE activities at any time to attend 'employment-related' activities at short notice
- the Department for Work and Pensions legislation on exempt work now allows earnings at the higher level of Permitted work without time limit (*see Memo DMG 7/17*).

Further information from INVOLVE

If you require further information about service user involvement at INVOLVE, please contact a member of staff at the INVOLVE Coordinating Centre: 02380 595628 or at involve@nhr.ac.uk.