# MRC/CSO Social and Public Health Sciences Unit Consultation Response

<table>
<thead>
<tr>
<th><strong>Title of consultation</strong></th>
<th>Consultation on Social Security in Scotland</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Name of the consulting body</strong></td>
<td>Scottish Government</td>
</tr>
<tr>
<td><strong>Why did the MRC/CSO Social and Public Health Sciences Unit contribute to this consultation?</strong></td>
<td>Social security systems and reforms are important social determinants of health which impact most strongly on groups who experience health inequalities. The Unit has expertise in this area which should be leveraged to inform policy if possible.</td>
</tr>
<tr>
<td><strong>Our consultation response</strong></td>
<td>SECTION 7 DISABILITY BENEFITS</td>
</tr>
<tr>
<td><strong>Should the individual be asked to give their consent (Note: consent must be freely given, specific and informed) to allow access to their personal information, including medical records, in the interests of simplifying and speeding up the application process and/or reducing the need for appeals due to lack of evidence?</strong></td>
<td>At present NHS patients are not asked to consent to the sharing of personal (i.e. identifiable) information within the NHS where such sharing is needed, for example, to provide continuity of care, although explicit consent is required for the sharing of identifiable information for other purposes such as research. Exceptions are sometimes made to the rule that explicit consent is not required, such as in the new SPIRE system for sharing general practice data. In its response to the recent National Data Guardian (England) Review of Data Security, Consent and Opt-Outs (‘Caldicott 3’) the Scottish Government made it clear that while there was a need to explain much more clearly to patients how and why information was shared to enable the NHS to deliver, evaluate and improve its services, it did not see explicit consent as a practical or desirable model in most cases: ‘offering consent opt-outs on data processing essential for delivering high quality care and core tasks (ranging from billing, administration, bench-marking, audits, screening, patient safety programmes, regulatory investigations of professional conduct, evaluations of clinical outcomes, statistics etc.) is disruptive, costly and can reduce quality and equity of care.’ The response also suggested that the distinction between primary (e.g. providing care) and secondary (e.g. research) purposes, should be dropped as both are needed to deliver high quality services, and there is wide public acceptance of the value of non-</td>
</tr>
</tbody>
</table>
commercial research. The same considerations apply to sharing information for administering benefit claims. It should not be assumed that consent is necessary, but sharing medical information for social security administration is a new development and the public should be directly consulted (e.g. through citizen’s juries or other deliberative methods) on whether a consent process is necessary, or whether the costs, in terms of administering opt-outs, and their effects on efficiency of processing claims, etc., outweigh the benefits in terms of safeguarding personal information.


**Would applicants be content for their medical or other publicly-held records, for example prescribing and medicines information or information held by HMRC, to be accessed to support automatic entitlement where a legal basis existed to do this?**

See above: Data sharing for clinical purposes is already widely practised, and accepted, although public awareness of the extent of sharing may be low. The legal basis for sharing such information is the Data Protection Act, rather than legislation specific to the use of NHS patient data. In its response to Caldicott 3, the SG was clear that any new legislation to strengthen the legal basis should be preceded by ‘a comprehensive public consultation and a wider public information campaign that does far more to show how essential information sharing now is for direct care’. Similar principles should be applied to the legal basis for information sharing to support automatic entitlement, and research and evaluation should be included, alongside administrative uses.

**Could the current assessment processes for disability benefits be improved?**

The current assessment process for PIP is based on an interpretation of the "biopsychosocial model" (BPS) developed by academic researchers including Mansel Aylward and Kim Burton. This is represented as permitting a ‘holistic’ approach to assessing the impact of illness or disability on an individual’s functioning, which goes beyond the medical model of illness by incorporating biological, psychological and social factors which influence ability to function. However, the psychological aspects of the BPS model seem to refer primarily to the role of the individual’s “dysfunctional perceptions, attitudes, and behaviour” (Waddell and Burton 2004 p.33). It is argued that these have a stronger effect on recovery than any physical symptoms. There is a presumption that people are positively incentivised to engage in ‘illness behaviour’ (ibid.)

Within the BPS model, symptoms which cannot be objectively measured are deemed to be subjective and “therefore at least partly a matter of perceptions.” (2004 p.24). The majority of common health problems, including musculoskeletal, cardiorespiratory and mental health complaints are described as ‘subjective’ (Waddell and Burton 2006). Prominent academic disability researchers have conducted an analysis of Waddell, Burton and Aylward’s publications on the BPS model, and found that many of their arguments are poorly evidenced (Shakespeare et al 2016). The very high rate of successful appeals against negative PIP decisions (63% at June 2016; Benefits and Work 13/6/16) would suggest that basing the assessment on the
BPS model has led to fundamental problems with the design of the assessment. In addition, the testimony of countless individuals, charities and advocacy organisations indicates that the assessment is often found to be humiliating and exhausting, and in itself can lead to a deterioration in claimants’ health (Guardian 26/9/16, Muscular Dystrophy UK 2016, Gray 2016).

There is currently little in the way of evidence to assess the relative success of different approaches to disability assessment (Baumberg et al 2015). However, we would recommend that the current assessment is replaced with a more appropriate approach which fully recognises the impact of symptoms on functioning. This should be developed in close cooperation with user groups and representatives.

REFERENCES
Muscular Dystrophy UK. Focus on disability benefits Assessing the impact of Government reforms on independent living Muscular Dystrophy UK 2016.

SECTION 9 COLD WEATHER PAYMENTS

Could changes be made to the eligibility criteria for Cold Weather Payments? For example, what temperature and length should Cold Weather Payments be made on in Scotland?

Cold weather payments may improve health even if they bring about small improvements in indoor warmth, but there is a case for raising the temperature threshold.

A Cochrane systematic review of the health impacts of housing improvement concluded that improvements in domestic warmth can lead to improved health, especially where the improvements are targeted at those with chronic respiratory disease. (Thomson, Thomas et al. 2013) The best available evidence to support these conclusions came from two large, well conducted Randomised Controlled Trials in New Zealand. Both these studies looked specifically at impacts on households where at least one member had a diagnosed respiratory condition. The warmth improvements were linked to small increases in thermal comfort in the home. In one trial looking at impact on children with asthma, the improvements in warmth were
reported as an increase in average temperature of 1.1°C and 0.5°C in the living room and child’s bedroom respectively. (Howden-Chapman, Pierse et al. 2008) (Howden-Chapman, Viggers et al. 2009) In the second trial there was an increase in average temperature in the bedroom of 0.6°C, and the average number of hours per day when the room temperature fell below 10°C fell by 1 hour. (Howden-Chapman, Matheson et al. 2007) These changes in indoor warmth may seem small (between 0.5-1°C), but this is in the context where the average winter temperature is considerably higher than in Scotland: in the 2007 study the average winter temperature was 10.9°C. (Howden-Chapman, Matheson et al. 2007)

These changes in indoor warmth led to improvements in asthma symptoms, as well as other measures of respiratory health, general health and wellbeing. In addition, the warmth improvements were linked to reductions in time off work or school due to illness. (Howden-Chapman, Matheson et al. 2007, Howden-Chapman, Pierse et al. 2008) From this work it would appear that further health benefits, particularly for those with existing chronic respiratory conditions, from cold weather payments may be achieved if the temperature threshold for payment was set at a higher level.

REFERENCES

SECTION 11 BEST START GRANT

What are your views on who should receive the Best Start Grant?

Universal benefits generally have better uptake than targeted benefits; child benefit uptake is 99% and Healthy Start Vouchers uptake is 70-80%. One way to maximise the uptake of BSG is to consider making it a universal benefit.

Do you agree that we should retain the requirement to obtain advice from a medical professional before making a maternity payment?

Evidence from our analysis of take up of the Health in Pregnancy Grant in Scottish Morbidity Records data, demonstrated that linking payment of the benefit to healthcare advice increased the take up of the healthcare advice and mothers
entered the antenatal system at an earlier stage than when the Grant was not in place.

**Are there any particular issues related to the nursery payment that you think we should consider?**

Consideration should be given to linking the payment to appropriate advice or services as in the maternity payment. This may have the effect of improving uptake or participation in the appropriate services.

**What are your views on our proposals in relation to the BSG application process?**

If linking the maternity payment to seeking health advice is taken forward, then consideration should be given to the most appropriate timing of seeking that health advice. The HEAT targets aim for pregnant women to book by 10-12 weeks pregnant. The Health in Pregnancy Grant required women to seek health advice by 25 weeks. The payment could be made at a later time point in the pregnancy but only on the condition that the advice had been sought by a certain time.

**What are your views on establishing an integrated application process for the BSG and Healthy Start?**

If the eligibility criteria for BSG and Healthy Start overlap then it makes sense to have an integrated application process.

**What are the advantages and disadvantages of this approach?**

The advantages are if there are limited resources then streamlining the information and application processes means that these resources are going into helping those most in need.

A potential disadvantage is if it makes the application process and form more difficult some people may not apply and therefore uptake will be decreased.

**Would the option to receive items rather than a cash payment as part of the BSG have benefits?**

Having access to cheaper goods through collective purchasing power might be advantageous. However, providing goods instead of a cash payment does not control how money is spent. Both goods and vouchers are forms of displacement; freeing up money the household would have otherwise spent.

**Which services should promote awareness of the BSG to ensure that claimants know about it at the relevant time?**

Currently DWP know about eligibility for Healthy Start as they provide information to Health Boards on take up of the vouchers. If the Scottish Government are committed to maximising the uptake of BSG, then one way to ensure this is to use data linkage to link maternity and birth records to benefit data and send information and
application forms directly to eligible mothers.

SECTION 21 SAFEGUARDING YOUR INFORMATION

Should the existing Scottish Government approach to Identity Management and Privacy Principles be adopted for use in our social security system?

We strongly support the adoption of the identity management and privacy principles. The principle relating to data use for research and statistics is essential if Principles 3 and 5 for the new Social Security system set out at the beginning of the document (that processes will be evidence-based and demonstrably efficient) are to be fulfilled. Likewise, evaluating whether the new system meets its long-term outcome of enabling people to live healthier lives in the community will require linked health and social security datasets. Existing surveys will not contain sufficient numbers of recipients for evaluation purposes, and even if new or expanded surveys were affordable, the use of linked datasets will open up a wider range of evaluation opportunities at much lower cost.

Do you perceive any risks to the individual? What solutions might be considered to mitigate against these?

The risks of breaches of privacy and confidentiality can be reduced to a very low level using procedures that have already been implemented to enable the sharing of health data for research and statistical purposes in Scotland. They include de-identification of data at the earliest possible stage in the process, the establishment of accredited regional NHS and university-based safe havens where data can be accessed, and a Public Benefit and Privacy Panel to consider novel, large scale and potentially contentious access requests. Systems to mitigate risk should be proportionate to the level of risk involved, and designed to be efficient as well as effective, in line with the new Caldicott principle 7 which recognises the duty to share, as well as to safeguard data.

Would you support strictly controlled sharing of information between public sector bodies and the agency, where legislation allowed, to make the application process easier for claimants? For example, this information could be used to prepopulate application forms or to support applications, reducing the burden on applicants.

Yes, but the purposes should be extended to include research and statistics. As noted above, the SG has taken the view that the distinction between primary and secondary purposes of data sharing should be dropped, as research, monitoring, evaluation, etc., are all essential to delivering service improvements.

When was the response submitted?

28/10/2016

Find out more about our research in this area
Health impacts of welfare reform (PIP assessments) and warmth improvements (Cold weather payments), methods of evaluating health impacts of social interventions (use of routinely collected data for research purposes):

http://www.sphsu.mrc.ac.uk/research-programmes/po/

Use of routine data to evaluate social interventions (Best Start Grant):

http://www.sphsu.mrc.ac.uk/research-programmes/in/

Who to contact about this response

Use of routinely collected data for research purposes:

Dr Peter Craig
Informing Healthy Public Policy
MRC/CSO Social and Public Health Sciences Unit
University of Glasgow
200 Renfield Street
Glasgow G2 3QB
0141 353 7559
Peter.Craig@glasgow.ac.uk

PIP assessment:

Dr Marcia Gibson
Informing Healthy Public Policy
MRC/CSO Social and Public Health Sciences Unit
University of Glasgow
200 Renfield Street
Glasgow G2 3QB
0141 353 7554
marcia.gibson@glasgow.ac.uk

Warmth improvements:

Dr Hilary Thomson
Informing Healthy Public Policy
MRC/CSO Social and Public Health Sciences Unit
University of Glasgow
200 Renfield Street
Glasgow G2 3QB
0141 353 7518
Hilary.Thomson@glasgow.ac.uk

Best Start Grant:

Ruth Dundas