

## **Scottish Care response to the consultation on the Centre for Data Ethics and Innovation**

**August 2018**

### **Who is Scottish Care?**

Scottish Care is the representative body for independent social care services in Scotland. This encompasses private and voluntary sector providers of care home, care at home and housing support services across the country. Scottish Care counts over 400 organisations as members, which totals just under 1000 individual services. Scottish Care is committed to supporting a quality orientated, independent sector that offers real choice and value for money. Our aim is to create an environment in which care providers can continue to deliver and develop the high-quality care that communities require and deserve.

In relation to older people's care, this sector provides 89% of the care home places in Scotland, both residential and nursing. There are more older people in care homes any night of the week than in hospitals – as at 31st March 2016 there were 873 care homes for older people providing support to 33,301 residents any night of the year.

Our members employed over half the total number of social care staff in Scotland, at over 103,000 workers.

Scottish Care has recently published a report called '*Tech Rights: Human Rights, Technology and Social Care*' (<http://www.scottishcare.org/wp-content/uploads/2018/08/Tech-Rights-Booklet-PROOF.pdf>). As well as making a series of recommendations, the report highlights the importance of ensuring principles of co-design, human rights and ethics are at the heart of the debate around data and AI, and technology more widely. We would contend this is especially the case in the social care of older persons, many of whom are already significantly impacted by being the subject of data, AI and robotic usage in health and social care dimensions and will be even more so in the future.

**1.**

### **Do you agree with the proposed role and objectives for the Centre?**

As an organisation we believe that it is fundamentally important that the Centre is dedicated to an ethical understanding of the gathering and use of data and AI. We consider that the recognition that the new technological advances are giving rise to uncertain economic and ethical issues to be completely accurate. We warmly welcome the establishment of the Centre and its focus on ensuring that future responsible innovation, design and use, is enabled and encouraged by means of fostering and promoting best practice, and where necessary anticipating and addressing regulatory gaps. We wholeheartedly concur with the aim to establish a governance regime – 'a set of norms,

rules and structures’ - that determines how data and AI can and should be used and would argue that this should be established within the norms of a developed human rights international framework. The current framework of human rights at national and international levels pre-dates the digital, data and technological advances of the last few decades. There will be merit in exploring with all affected by the use of data and AI the extent to which new legal safeguards should be introduced. We would argue that these should be based upon human rights principles. For instance, in the area which most impacts upon social care, should there be a developed human right that gives to citizens the right for care and treatment to be ultimately administered by a human being, whether or not robotic assistance is involved in the overall care and support.

The role of the Centre in drawing on existing bodies, academic centres and regulators is self-evident. We would strongly encourage and advocate for an inclusive approach to citizens and organisations who are out with the ‘technological world’. Our recent report cited above highlights the importance of co-design, collaboration and partnership in the development of future use of DATA and AI.

We would hope that the AI Council itself is reflective of both national and user contexts and breadth.

In its developing work, Scottish Care would hope that the Centre would seek to advocate and develop a core set of principles on which the ethical use of data and AI could be rooted and established. Our recent report offered the following as a starting point. We would suggest that the wide sector acceptance of a Code or Charter would be beneficial for the work of the Centre.

**‘The use of technology:**

- must be to the benefit of the individual and the common good
- cannot be used to restrict or remove any human right but should seek to enhance and achieve the human rights of the individual
- should enable and foster independence if so desired
- has to take account of the unique character and individuality of the person, including characteristics of sex, race and ethnicity, disability, sexual orientation and age etc.,
- should always be non-discriminatory
- should be accessible, understandable and transparent
- should be fair and equal in its treatment and use
- should enable an individual to flourish and achieve their full potential
- should be with the consent of the individual and accord with the previously articulated wishes and views of the person
- should be accountable to the individual whose data is held and enable them to check, edit and control that data
- should not be used to harm, destroy or diminish another
- should enable and augment human presence rather than wholly replace it.’

(From *'TechRights: human rights, technology and social care.'*, Scottish Care, June 2018, page 47-48, <http://www.scottishcare.org/wp-content/uploads/2018/08/Tech-Rights-Booklet-PROOF.pdf> )

2.

**How best can the Centre work with other institutions to ensure safe and ethical innovation in the use of data and AI? Which specific organisations or initiatives should it engage with?**

Scottish Care considers that it is imperative that the Centre recognises the different jurisdictions which are a reality within the United Kingdom. In particular Scottish Care has made a series of recommendations to the Scottish Government and other stakeholders to embed an ethical and rights based set of principles, a Charter, into the further developments and use of technology, (including data), most especially within social care.

We have contended in our latest study<sup>1</sup> that it is important in seeking to achieve public acceptance of data and the way in which it is used, and thus to reduce and diminish, an apparent trust deficit, that end users and those most impacted by data should be involved at all stages of design, deliberation and analysis. We would suggest it is, therefore, important that the Centre seeks to prioritise gaining the perspectives of social care service users, workforce and employers. It is only through such engagement and involvement that the desire to foster further demand for AI and data-driven innovations will be achieved.

3.

**What activities should the Centre undertake? Do you agree with the types of activities proposed?**

In appreciating the necessity for the Centre to be responsive and dynamic, we would agree that the description of the Centre's core activities is appropriate and accurate. As stated above we would commend the support of the publication of principles and standards that guide innovative use of data and AI. Whilst we recognise that it is frequently much better to develop voluntary codes, we would contend that because the issues are of such significance that it might be sufficient for codes and standards to be voluntary only.

4.

**Do you agree with the proposed areas and themes for the Centre to focus on?**

Within these or additional areas, where can the Centre add the most value?

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<sup>1</sup> See *'TechRights: human rights, technology and social care.'*, Scottish Care, June 2018, <http://www.scottishcare.org/wp-content/uploads/2018/08/Tech-Rights-Booklet-PROOF.pdf> )page 23-24.

Whilst accepting the six areas in which the Centre could undertake project work are reasonable, we would add to these that issues of equality, access, human rights and discrimination in both the development of AI and data in the realm of health and social care should be a distinctive priority area. Part of this would be the extent to which the citizen has the ability to access, change and control data held on their behalf as Big Data and associated algorithms develop. We would also suggest that there needs to be a particular focus on the use of AI and robotics in social care which has been highlighted as an especial area of ethical challenge and concern.

5.

**What priority projects should the Centre aim to deliver in its first two years, according to the criteria set out above?**

As stated above Scottish Care believes that the use of AI and data in the social care (rather than in the health supports) of individuals is a critical area for ethical and human rights considerations. We would suggest that if this is proactively developed and addressed that the lessons will have resonance and transferability into other sectors.

6.

**Do you agree the Centre should be placed on a statutory footing? What statutory powers does the Centre need?**

It is critically important that the Centre is able both to be independent and to act as a n advisor to Government and regulatory bodies. Establishing itself as a statutory body would be helpful. It also has to develop an ability to resonate with all the devolved administrations and the work carried out therein.

7.

**In what ways can the Centre most effectively engage stakeholders, experts and the public? What specific mechanisms and tools should it use to maximise the breadth of input it secures in formulating its actions and advice?**

We would suggest that the Centre establishes, for the Scottish context, a Scottish Advisory Group. That body could utilise a range of methodologies including focus groups, structured interviews, etc to engage with Scottish stakeholders.

8.

**How should the Centre deliver its recommendations to government? Should the Centre make its activities and recommendations public?**

An annual report supplemented by any further necessary reports and publications would seem entirely reasonable. Absolutely yes. It is imperative in seeking to ensure a framework of ethical rights at the heart of data and its usage, that a principle of open transparency

should result in the work of the Centre, and in the open publication of its activities and recommendations.

If you would like any further input or information, please contact:

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