



Llywodraeth Cymru
Welsh Government

MEETING

COVID-19 Moral and Ethical Advisory Group Wales meeting: 8 October 2020

Minutes for the COVID-19 Moral and Ethical Advisory Group
Wales meeting held on 8 October 2020.

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Actions

Action	Responsible
Secretariat to request terms of reference of existing CECs.	Secretariat
Examples where digital exclusion have been an issue to be sent through to secretariat	All
Digital exclusion paper to be published with minutes	Secretariat
All members asked to share examples with Rhian Davies to consider COVID-19 related deaths for disabled people to aid evidence collecting	All

Attendees

Heather Payne (Chair), Aled Roberts, Aled Edwards, Martyn Jones, Alison Mawhinney, Helena Herklots, Kevin Francis, Alison Parken, Ben Thomas, Rhian Davies, Viv Harpwood, Shavanah Taj, Carol Wardman

Meeting note

1. Welcome, Apologies & Introductions

The Chair made introductions and noted apologies.

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2. Previous minutes

The Chair asked group members to provide any comments or amendments regarding the note of the last meeting to the Secretariat.

Actions: all items on agenda.

A brief update was provided on work regarding BAME socio-economic report, advising a phone line launched to help provide an accessible first port of call for information on a range of specialist, mainstream and community organisations, with call handlers speaking a range of community languages.

3. Clinical Ethic Committees

The Chair advised the Welsh Government are looking to establish a Wales wide approach. A 2 hour meeting has been established for 23rd October with a wide range of colleagues. Purpose of the meeting to consider COVID-19 related ethical questions.

Ben Thomas will speak at the meeting to prioritise current issues and the plan for later.

Action: Secretariat to request terms of reference of existing CECs

CMEAG members queried the role they could play and how they could communicate with the existing CECs. Members were also asked whether they saw a benefit of a national group in the longer term. One potential issue is in regard to aligning different views from different fields of expertise. These competing understandings could tend to undermine equity and consistency.

One thing in common at national and local level is the approach to embed the use of an ethical framework in decisions in circumstances where

decision makers are not aware there is an issue. Different perspectives viewed as vital.

There is a historical precedent for committees to treat disabled people as vulnerable, rather than equal partners and members would like to ensure this is challenged.

Chair and Secretariat to draft agenda and issue.

4. Digital Exclusion

Alison Mahwinney provided an overview of issues relating to digital exclusion and human rights perspective relating to older people and other groups. These areas of concern include accessing information, lack of means to research and isolation. The inability to access services falls under Freedom of Expression and the right to receive information as the public have a right to be informed on public interest issues. Information alone is not the important part, it is how the information is delivered.

A range of options is available to challenge whether information is and will be provided to relevant population groups, including judicial review. UN committees periodically review mechanisms in which countries provide this information and the UK is due for review next year. Any recommendations or advocacy tools from these reviews can be used to a driver to progress change.

Martyn Jones advised he would be happy to take this paper to Equality and Human Rights team. The Welsh Government has previously agreed the importance of ensuring accurate and accessible information available and questions raised as the current circumstances of the Welsh Government engagement policy regarding this.

It was outlined that scams and online crime are also a huge concern and questions regarding whether impact assessments have been considering issues such as this. Another issue is the accessibility of digital communications. Many of the public health messages over the last few months have not been accessible to disabled people for example, BSL, Easy Read, image descriptions, etc.

There is work required to connect the different inequality dimensions to digital exclusion. For example, huge similarities regarding issues affecting BAME people. Similar issues are facing the Welsh language online, as practical barriers raised due to timescales. Public Health need to provide information in a timely manner and lack of appropriate information can cause a significant risk.

The group feel this should be regarded as a critical area as older people become to simply accept they are excluded. Questions regarding who is responsible on public bodies and the State to ensure people receive the information they require.

Action: Any examples where digital exclusion have been an issue, please send through to Secretariat.

Action: Accompanying paper to be published

1. Disability death due to COVID-19

Rhian Davies advised a steering group has been set up to provide report on disproportionate numbers of death for people with disabilities. Current aim is to publish by Christmas. The ONS have reported on number of deaths related to COVID for disabled people between March and July 2020. Definition of disabled based on 2011 census. ONS found more significant the condition the more likely death could be an outcome.

Findings show disabled people make up 6 in 10 deaths during this period in the UK, and in Wales this number is 68%. A higher number of deaths reported amongst disabled women. In September 2020 a Joint Committee on Human Rights published a [report on impact to Human Rights and breach of Right to Life](#), criticizing decision making for admission to hospital and discriminate against disabled and older people.

In addition it has been felt media coverage has been disappointing, with terminology including an expectation for disabled people to be more likely to die.

To raise these as a prominent issue, metrix and monitoring in real time is required to understand the issues faced.

The prevalence of poverty and COVID-19 related deaths was considered. Whilst it is considered a significant factor, disability still higher outcome for death, but it is possible there are compounding factors broader than just disability. Recent headlines regarding deprived communities are twice more likely to contract COVID-19. This needs to be more nuanced - deprived are disproportionately women, disabled, BAME and young.

It was suggested this summary info could be shared with health boards – especially as evidence around admission policy needs attention now.

Action: All members asked to share examples with Rhian Davies to aid evidence collecting.

Action: Highlight to NHS and ensure measuring disabilities as basic data item for any contact.

2. AOB

None

Next meeting in two weeks as planned (22nd October)

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