General comment on Chapter 1.

One person queried the need for another layer of bureaucracy in the R&D process, particularly when a company is involved

Question 8: Would a trial register be of benefit to patients seeking trials? Would it be an effective way to partner patients with researchers? Is there a danger that expectations of taking part could be unfairly raised?

We support the inclusion of a range of Scottish publics within medical research in Scotland and elsewhere within the UK; however, any trial register must be vigilant in refraining from advancing the ‘therapeutic misconception’ in patients. The limitations of research participation, and the actual and likely goals of the research, must be explained clearly to patients in the interests of promoting more informed consent (Pickersgill, 2010).

Question 10: What proportion of CSO funding should be available for deployment in new research initiatives relevant to the NHS? In what areas should CSO seek to disinvest to free up resources?

Although we are mindful of the finite resources of the CSO, we are concerned about advocating for *disinvestment* in any of the key research areas that the CSO currently, and rightly, funds. We prefer instead to note areas that are often overlooked and where investment must continue at (at minimum) current levels. Specifically in need of further support are: mental health (including: basic biomedicine; psychological therapy; social and ethical dimensions), public health policy, and qualitative research with patients and care-providers.

Question 13: Are there other key areas of partnership CSO should be seeking to build?

The CSO is to be congratulated on its wide-ranging existing partnerships. However, there is a notable lack of partnerships with mental health organisations, such as the Mental Health Foundation, which should be addressed. Likewise, partnerships with organisations like the Royal Society of Edinburgh and the Young Academy of Scotland have much to offer for the CSO’s important work about health policy

References:

Pickersgill M (2011) Research, engagement and public bioethics: promoting socially robust science. Journal of Medical Ethics, 37(11): 698-701 Link