PRG Feb 15

Present: LP, BE, IG, AT

In attendance AV

Introductions: AV explained she was in attendance to try to gauge people’s reaction to the proposed re-vamp of the Care data project.

Discussion around perceived/ real reasons for failure of previous attempt: comments included people almost instinctively distrust anything politicians say, concerns around security- too many documents have been lost too often for people to trust security; the actual document sent to homes was remembered by only one person present (not the presenter), who described as looking like an advert from a pizza chain or similar, this was considered to be very disrespectful of the public, as if govt thought informed public input was irrelevant; press were certainly against it.

Proposed new leaflet was circulated-discussed at some length- considered to be very poor. The cover was ‘migraine inducing’ in its design, the information poor and largely incomprehensible; much of terminology was only vaguely related to the English language. The easy read version was marginally better but too long, it was felt that many people would give up by page 3 or 4.

Once again this is an ’Opt in’ rather than an ‘Opt out’ project so anyone who simply does nothing will be assumed to have agreed even if they have not understood the need for action on their part; - which given poor quality of the proposed information leaflet would not be surprising.

Reasons for information being collected did not seem to entirely add up either. Allegedly it is aimed at developing better more responsive health care. Pointed out that anonymised disease prevalence could already be obtained from the IT systems in place as could prescribing information so it was already possible for example, to see if any one means of treating a particular disease was more effective. It was felt that the need for postcode and other additional information was not made out especially in view of cynicism around security of information.

AV was unable to confirm whether or not those who opted out in last attempt to bring this in would need to opt out again or whether they would be assumed to have consented if they failed to react this time.

Noting that Leeds is a pathfinder for this; the question was raised as to how useful the data would be in cases where people moved house to another area which was not part of project – though eventually the whole country will be- how will information be useful if it relates to those who previously lived in an area? How will be information be updated when someone moves house? Ease to see how they could be added in but how taken off form previous address?

What is there to stop future governments deciding to sell this information?

Conclusion was that while it had been useful to have some input there were a great many questions that needed answered.

AV to send some of documents in e format to LP for wider consideration among practice colleagues and other co- workers.