

To:

Steve Ham

Chairperson of End of Life Care Board

NHS Wales

27/11/2019

Dear Steve,

Re.: Progress with Advance & Future Care Planning Strategy (AFCP) Group and decisions on next steps

I wanted to give you an update, and in turn ask you your decisions on next steps to take from here.

As a key output from our AFCP group, we held an all Wales Future Care Planning Conference earlier in 2019, with attendance from all over Wales and patient and carer involvement. We have collected contributor data from this event that we are evaluating in two stages. First off, we will give an interim report on what delegates felt would be a useful way forward. Secondly, we will task an independent researcher to conduct a Framework Analysis, which will guide us, we hope, towards a national consensus on how we operationalise all of this, and what All Wales AFCP documents should look like. Learning from this conference will inform the evolving content of AFCP in Wales. Feedback also included requests for good link up between all the different electronic systems, including from primary care and secondary care, so that Advance and Future Care Plans are widely accessible and visible. This brings me to the next topic, the need for an electronic platform to host such documents and the specification we have ratified.

A system that makes patients' wishes available to professionals needs to be a key component of electronic health and care records. To this end, you will remember that a short specification document was written in 2018 and that this went through the relevant groups, including PCIG. We have subsequently produced a more detailed, long version of this document, which was agreed by AFCP Group earlier this year and which was presented to End of Life Care Board in the October 2019 meeting. You will recall that this held 145 points of importance, ranging from consent, to Code of Practice for Information Management compliance.

With this long specification document in mind, the AFCP Group held an event at Welsh Government on the 9th October 2019, where three off-the shelf provider companies for electronic Advance and Future Care Planning made presentations to our group. These three providers were selectively chosen after reviewing the worldwide market for this type of product, and after consultation with English NHS Trusts with experience in procuring for this. We also discussed this with representatives from NHS Digital. At the supplier day, presentations focussed on the companies' experiences when implementing and rolling out electronic A+FCP, how they tackled problems in this highly complex area, and what excellent sharing of care looked like. The companies were "MyDirectives" from the United States, "Black Pear" from the UK, and "Co-ordinate My Care" from the UK. These pitches

were recorded for all members for the group who were unable to attend and were subsequently sent out, with the accompanying PowerPoint Presentations and minutes of the discussions.

The AFCP group considered all the pitches and ranked them in order of how well they fulfilled the long specification document.

By an overwhelming majority, Coordinate My Care was the preferred product, with the best fit with our electronic specification. The group (which includes a patient representative) were also positively influenced by the experience they have in overcoming the challenges they have faced over years of working with the NHS in England.

I have since spoken to Rhidian Hurle, who, as a member of the AFCP group was also at these presentations. He feels there is scope for NWIS to work with one of these companies.

One of the remits in the Terms of Reference in our group was to advise you on our opinion for next steps. Our AFCP Strategy Group have contemplated the following options:

- **do nothing further**
- **work solely with NWIS**
- **work with external provider CMC to integrate into NHS Wales**
- **work with another company**

Action three, i.e. working with CMC, is their preferred option.

I hope this is useful to you in deciding on next steps. It is clear to all of us that once a decision is made on whichever option above, but in particular, the external provider options, a plethora of detail will need to be looked at before anything further can happen, so we are under no illusion about the significant workload, once this step is taken. We would of course be happy to discuss the options in more detail if you wish.

Yours sincerely,

Dr Mark Taubert

Chair of Advance Care Planning Strategy Group for Wales

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