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Emergency Information Services Exploratory

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	o E = exploratory report
	o L = lab report
	o F = factory report
	o S = summary document
	o LR = literature review
	o RR = research report
	o MR = market research
	o MAP = mapping
	o V=video
	o O= other

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Purpose of document	exploratory report
Event detail (delete row if appropriate)	Exploratory held by the Alliance and DH held the 20/10/16 in Glasgow to discuss the prospect of employing a digital health solution for the emergency information services. The service Meditext was employed in the workshop.
Project detail (delete row if appropriate)	Report on the exploratory for Meditext
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Related projects	Names and doc reference numbers
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Emergency Information Services Exploratory | 20/10/16 | Bath Street, Glasgow

The Alliance and DHI hosted an exploratory to allow relevant stakeholders to discuss the prospect of employing a digital health solution for the emergency information services. This solution was called Meditext, which is a subscription service which will send vital medical information via text to a first responder at the scene of an emergency. This solution has been endorsed by police who claim that it can take up to 6 hours to identify a person's identity at the scene of an emergency and they have expressed an interest in this service. Paramedics have also reflected this interest. This text service could have great benefit for people who suffer from long term conditions such as Diabetes, Epilepsy and mental health issues.

The Glasgow School of Art and Design produced the exercise for which the participants could discuss the utility of this service. The 15 participants were split into 4 groups, each of which were given a different case study. In each of the different scenarios, the Meditext service was employed. The participants were asked to read their case studies and dissect the story to ascertain what benefits and risks there were to using this service as well as prospective opportunities to improve the current service or healthcare system. Each group were asked to define the people/organisations involved in the scenario, their actions and communications. Issues arising from these actions were identified along with opportunities.

Scenario 1: Charlie

Charlie is a 72-year-old man with dementia who lives in a carehome which he enjoys. However, the high turnover of staff and the less frequent visits from his son are making him distressed. The group identified those involved in the scenario as:

1. Charlie;
2. Charlie's son;
3. Carehome staff and
4. People in general.

Charlie's son and the carehome staff persuade Charlie to make use of the service so that he can retain his independence. At first Charlie is sceptical but his son explains that it will be best for him to do this. In the end Charlie's son is satisfied that his father will be safe when he goes out since his vital medical information detailing his dementia will be made available to people if his Father gets into difficulty. The group identified various issues within this scenario.

Consent: One major aspect was the idea of consent– does Charlie understand what his son and staff are asking him to do? The fact that Charlie has dementia means that he may not be able to give consent

and so this is something which must be considered when offering this service to people. The power of an attorney may be required in some cases where people cannot give this consent.

Stigmatisation: Many people with long term conditions currently wear pendants or something similar which presents this information in an emergency. This is an updated version of that and may in fact be better since it is anonymous until it is required.

Independence: Charlie's independence is limited since he has dementia and is living in a carehome and so this service could ensure his safety when he is not in the carehome. It could allow him to retain the independence he has until his dementia progresses to a state where he would need to remain within the confines of the carehome.

Choice: These services must be a choice and people can call upon the service if and when they want to use it. However, there must be a choice as to how much information the person wants to input into the text service. In Charlie's case it was felt that the service was being pushed onto Charlie – did he really feel comfortable with it? There is definitely a benefit for Charlie's son but what about Charlie?

Data Protection: this was a theme which dominated the workshop to some extent. It was evident that there was a difference in opinion between those who were comfortable sharing sensitive health information with others and those who were not. One resolution to this from the perspective of those who were not comfortable could be to only have the person's age, name and CHI number so that only healthcare professionals can access the data. However, it should be at the individual's discretion how much sensitive information is made available in the text. Again the implications of choice are important here.

Data Access: currently, it costs money to access your own health-related data. It should be free. Should this service be free too? Is £24 a year the same concept as paying for your health-related data? However, the profits go to charity which is good.

The opportunities which arose from scenario 1 were:

- There should be more education and awareness surrounding this kind of service so that more people are aware and can make a positive choice for themselves.

- Patients should have access to their health data so that they can feel empowered to use these services. If they cannot view their own data, why would they feel comfortable putting sensitive information into a text for a stranger in the public to read in an emergency.
- Having reviews of the service so that the service can constantly be improved through patient experiences.
- A partnership with third sector organisations and the NHS to build confidence in the service will be good for its scale up.

Scenario 2: Jenny

Jenny is a 34 who lives alone, but in close proximity to her sister, who has a history of mental illness including severe depression and anxiety. She was diagnosed as bipolar when she was 26. The case study provided to the participants described a scenario in which Jenny finished work early at 4pm, following this she visited the library to check for a specific book (Paul Wellers post Jam biography). She was unable to check the book out but was given a short two-hour window to have access to the book. This triggered a manic episode, Jenny felt restless and began talking to others in the library, upon being ignored she became agitated and began shouting. Library staff the phone the police, who arrive and determine Jenny is drunk and disorderly, upon searching Jenny they find a card indicating she uses an emergency information service. Through information received they contact Jenny's sister and the issue is resolved. The participants presented with this scenario were asked to identify the characters involved in the scenario, their actions and their communications with other characters. They identified the following characters from the scenario:

1. Jenny
2. Library staff
3. Members of the public
4. Police
5. Jenny's sister

The group identified the actions and communications outlined in the case study and mapped them out in a timeline of the scenario. Following a short break, the group reconvened and were tasked with discussing issues and opportunities for action they saw within the case study.

For the group discussing Jenny's case study the two main issues discussed were Jenny's lack of awareness of her own triggers for her condition and the fact that despite Jenny's using of an emergency information service she had to be searched before any benefit from the service could be made. These

issues directly inspired some of the opportunities raised by the group, it was suggested that Jenny should have to undergo counselling and/or training to understand her own condition better. This sparked a trend in the opportunities of raising public awareness for recognising symptoms for mental illnesses, it was also suggested that police officers should undergo better training to address sufferers of mental illness as should the library staff (as well as other public service workers). Because of her condition, it was suggested that Jenny could use multiple methods of communication for her emergency information service, the idea that Jenny could use wearables that linked to her emergency information service was discussed by the group as a whole and it raised concerns of stigmatisation. This idea was coupled with the idea of possibly combining the service with a location based data transfer from a centralised database. This would mean that when she enters public service establishments she can be identified as an emergency information service user, therefore negating the need for her to be searched or placed in any embarrassing situations when suffering one of her episodes.

Scenario 3: Helen

Helen is 48, she works fulltime in a job that requires frequent travel, her partner works part-time and she has two teenage children. She has recently taken up running. In her youth, Helen suffered from severe psoriasis that required surgical treatment and was very ill after the birth of her two children. She also suffers from Cardiomyopathy, which in extreme cases can cause sudden fainting. The case study provided the participants with a scenario in which Helen goes for a jog in the morning before work, on her jog she fainted and hit her head. A passing car stopped to check on her and call an ambulance, they informed the operator that Helen hit her head but wasn't bleeding. Upon arrival ambulance staff assessed Helen and deemed it necessary to take her to A&E. The Staff checked Helen for her Id and found a card with a mobile number on it, directing them to text it to receive emergency medical information. They received the contact details of Helen's partner and information relating to her heart condition (including her symptoms and current medication). The ambulance staff called ahead to A&E with an update on Helen's condition, because of this hospital staff could treat Helen for both her injury and the condition that caused it. Following treatment Helen was visited by a cardiac specialist who noted that Helens blood pressure was low and kept her in for observation. Helens condition has resulted in Atrial Fibrillation, she was prescribed new medication and sent home, where she updated her emergency information.

The group going through Helens scenario raised several issues and insights. The first of these was the existence of an information black hole when a person's circumstances/medication change. Their emergency information summary can only be updated by a lead GP, because of this if they update their

own summary there may be a period when there are two conflicting sources of information. A solution to this was that multiple people should be able to update the Key Information Summary to ensure that a person's information is as accurate as possible.

Another issue raised was that ambulance staff do not regularly search people they find unconscious or incapacitated, this means that they do not find the card let alone access the required information. The opportunity to combat this was that ambulance services could be instructed to search patients, or for people to have different methods of communicating their number to retrieve their emergency information. Though this raised another issue of stigmatising patients using wearable communication devices. Another opportunity raised was for police, most likely the first on the scene of an emergency, to be trained and/or involved in the emergency information service.

The final issue raised was that there is currently no way for ambulance staff to send information to A&E in a written format leading to the possibility for miscommunication in the verbal transmission of information. The method to combat this issue was for ambulance crews to use text messages to communicate with A&E.

Conclusion

The most discussed issue in using the Emergency Information Service was that first responders to any scene still have to identify the individual in need of care as an Emergency Information card holder. This caused concern as people requiring emergency care may not always be able to communicate their use of the service. This coupled with the fact that a first responder may not search the card holder if they are unconscious or incapacitated renders the service somewhat redundant. There were concerns shared throughout the groups regarding data protection for card holders and issues with regards to consent for data transfer involving card holders with mental health conditions. The groups felt that patients required a more in depth knowledge of the service they are using, and access to their own health records to combat any issues of stigmatisation or consent. It was also discussed that emergency service staff required specialist training involved educating staff on the use of Emergency Information Services and how to recognise individuals with long term medical conditions and how they could interact appropriately with them.