

A Scottish Ecosystem for Innovation

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Document reference number	DHI+DDMMYY+doctype+000X <i>DHI030316E0001</i> <ul style="list-style-type: none"> ○ E = exploratory report ○ L = lab report ○ F = factory report ○ S = summary document ○ LR = literature review ○ RR = research report ○ MR = market research ○ MAP = mapping ○ V=video ○ O= other
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Publication date	3/3/2016
Revision date	
Revision number	

Purpose of document	Report on Exploratory Express on Electronic Health Records in Scotland
Event detail (delete row if appropriate)	“How can health and care data work together to benefit citizens and those delivering health and care services” – Exploratory Express, 3rd March 2016, Maxim Park

Related projects	Names and doc reference numbers
Keywords	Electronic Health Records; EHR; data sharing

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Report on Exploratory Express on Electronic Health Records in Scotland

The DHI KER-team ran two consecutive Express Exploratories at the second part of the Scottish Ecosystem for Innovation on Health and Social care integration. The Scottish Ecosystem for Innovation is formed by the DHI, the Alliance, Joint Improvement Team, eHealth, NHS, NHS24 and SCTT. The event was held at the Maxim offices at Eurocentral in Glasgow on the 3 March 2016.

The title of the workshop was “How can health and care data work together to benefit citizens and those delivering health and care services”. We chose as the basis of the workshop the work the DHI has been carrying out with the Scottish Government on Electronic Health Records. Sanna Rimpiläinen from the KER-team and Stephen Milne, the DHI Saltire Fellow, ran the workshop. Each workshop was 60 mins long, requiring the Exploratory tasks to be tightly focussed.

The aim of the workshop was to inspire the participants to think about Electronic health records and the types of data they would require to have access to either as a health and social care professional or as a patient, and with that in mind, what kinds of requirements would they have for an ideal electronic health and care record service.

The workshop started with a short, 10 min presentation introducing four different EHR systems¹:

- VistA, an open source system
- Cerner Millennium, a system operating on a closed platform
- Athena-health, a cloud-based system, and
- Data Exchange Layer making diverse EHR-systems interoperable (e.g. Infoway in Canada; e-Archive in Finland and X-roads in Estonia)

The first workshop was full with 20 participants, the second workshop had eight. The participants came from a variety of backgrounds, from policy making to pharmacy to health and care to IT-engineering etc., and were seated around four tables, each accommodating five people. Each table had been allocated a role, either that of a *social worker*, a *community nurse*, a *GP* and a *pharmacist*.

The first task (7mins) asked the participants to consider from the perspective of the allocated professional

¹ The presentation is in Appendix 1

which types of data and information they would need to access on an electronic health and care record system as part of their role, and then draw up a list of the three to five top priorities. Each table had one minute to report back to the rest of the group what their top priorities were.

In the second part of the workshop the task was flipped around, and the groups had to think from the point of view of a patient or a service user what types of data they would be willing and unwilling to share with the professional whose role they had played in the previous task. The groups had five minutes to think about this task, and list the three to five top priorities for the patient/service user point of view. Again, each table briefly presented their findings to the rest of the group.

The final task was for the groups to identify, based on the thinking they had done during the previous two tasks, which would be the most important functionalities of an ideal EHR-system, and why. The groups were given seven minutes to list the top three to five most important functionalities of these systems.

Those representing GPs would like to access, among other things, key areas of patient medical history, the patient generated and collated health data, predictive health information and analytics and clinical decision support. The “pharmacists” would like, for example, to be able to monitor diagnostic and referral data, and patient use of and reactions to medication; to have access to ePrescription facilities and cost management of medication. The “pharmacists” also noted that pharmacies could play a much bigger role than they currently do in the health care system by carrying a great responsibility of managing longer term conditions and by being the first point of contact for triage.

The groups approaching the topic from the perspective of Community nurses emphasized the importance of having an access to the goals of care and patient medical history, medical and lab results, allergies and other basic background information. They would also like to have a shared community message board with social services, as well as to be able to input data to share directly with medical staff and the patient’s carers.

“Social workers” would like to see the patient ID information, and data on who generally is involved in the care of the citizen; their mental health status, medical/health care and housing information, citizen’s care packages, and even their carer’s health information. The group also suggested the social workers would benefit from receiving real-time, up-to-date information and alerts and alarms to help with decision making.

Flipping the task around, however, it transpired that as “Citizens” some of the participants were far less willing to share their information with the different services. **Each group emphasized the citizens’ right to control the data sharing and to decide what information to share with whom and under what circumstances.** The participants seemed the most critical of sharing information or personal data with social workers, as well as with pharmacies and pharmacy staff, primarily because it was not considered as relevant for them to know have access to citizens’ personal, sensitive information as this might be for medical staff. One group suggested devising a tiered access to citizens’ medical data. This might mean nominating certain pharmacies or pharmacists to have wider access to different levels of personal data in specified circumstances. On the other hand, it was also noted that **it would be useful for the citizens to know what data is necessary and beneficial to share with what agencies in order to get the best care available.**

An ideal electronic health and care record system was described as secure (with tiered access), accessible from anywhere at any time, ideally mobile, easy to use and share data on, capable of providing real-time, accurate information and analytics, and as accessible by multiple agencies. It was also noted as useful to be able to gain access to more information if the circumstances so required.

The outcomes of this workshop indicate that while the requirements for an ideal electronic health and care record system are quite similar across the different agencies represented in this exercise, the different professional groups would require a lot more access to citizen data bases than what the citizens are willing to grant them, more specifically outside of health and care services. Citizens want to be in control of their own data and decide who to share these with. At the same time, the citizens will need educating about which data are necessary to share with which agencies in order for them to receive the best care available.

	Group 1, need access to:	Group 2, need access to:	Group 1 Patient willing to share with:	Group 2 Patient willing to share with:	Requirements for HER Group 1	Requirements for HER Group 2
GP	<ul style="list-style-type: none"> Hospital admissions and discharge dates Medicines, pharmacy information Insights into prevention of illness Predictive health information Personal data gathered by the citizens "My data" (generated by IoT) 	<ul style="list-style-type: none"> Key areas of medical history of patient Patient health information (e.g. exercise, lab tests) Patient support network Area specific incidents of X Predictive health information <p>Secondary conditions</p>	<ul style="list-style-type: none"> Community involvement in the care Might not share: financial information <p>Want to have control over data but to share the relevant information to get the care needed</p>	<ul style="list-style-type: none"> Immediate lab results Interface to log day-to-day readings Self-reported data Interactive interface to see what is going on in the EHR (recommendations) <p>Ability to have remote contact with GP</p>	<ul style="list-style-type: none"> Accurate, up to date, secure Fast access 24/7 Easy to use Multiagency use Automation of process <p>Analytics</p>	<ul style="list-style-type: none"> Secure, comprehensive Easily accessible Real-time reporting Modular access -> tiered access to data by professionals/services -> Certain rules to govern that Innovative <p>Cloud-based</p>
Pharmacist	<ul style="list-style-type: none"> Monitoring diagnostic data Apps to follow up patient use of medication and reactions to medication Medical history ePrescription Patient data and referrals 	<ul style="list-style-type: none"> Shared data and alert systems Long term care management -> moving care responsibilities to pharmacies First point of contact for triage Prescription and referral rights 	<ul style="list-style-type: none"> Not happy to share data in the first place - there is no formal recording of data at pharmacies <p>On the other hand: certain cohorts might be happy to share their data, e.g. cohorts with multimorbidities</p>	<ul style="list-style-type: none"> Willingness to share depends on the person Health info - tiered access on data by pharmacists/ pharmacies required Ability to share other info round preventative medicine -> to be 	<ul style="list-style-type: none"> Easy to share data Based on standards Patient able to access and edit their own data Mobile access <p>Provides alerts and information to patients</p>	<ul style="list-style-type: none"> Secure and cloud-based Real-time event calendar User input ability Good interoperability User-friendly Data-security -> tiered access

		<ul style="list-style-type: none"> • Cost management of medication <p>Linking to social care</p>	without network support	standardized into a service		
				Long term conditions management		
Community Nurse	<ul style="list-style-type: none"> • Goals of the care • Medication, medical history, medical and lab results, allergies etc. • Community message board with social services • Demographic details 	<ul style="list-style-type: none"> • Accessible from anywhere • Patient history, basic info (background info) <p>Inputting info to share with docs and family - > holistic care approach</p>	<ul style="list-style-type: none"> • Goals of care • Communications • Medication <p>The information available to GP/NHS generally</p>	<ul style="list-style-type: none"> • Depends on the person (what to share) • Might not want to have data shared with family <p>Possibly not willing to share medical data</p>	<ul style="list-style-type: none"> • Data system • Accessible 24/7 • Able to share information easily • Secure • Ability to do analytics, pick trends <p>Affordable</p>	<ul style="list-style-type: none"> • Mobile access • Secure • Easy to use • Easy data entry, connected to real-time events • Tiered access • Different categories of patient medical history <p>Advice, education to patients</p>
Social Worker	<ul style="list-style-type: none"> • ID • Circle of care (emergency contacts) • Medical history/care path • Alerts and alarms • Legal alerts 	<ul style="list-style-type: none"> • Real-time, accurate information: primary care/healthcare • Carer's health data • Acute care, A&E data • Any outpatient appointments • Care packages • Mental health information • Housing info 	<ul style="list-style-type: none"> • Not willing to share: location, activity, who you are with, mental health state, sexual health, medication <p>Might want to have access to: relevant services</p>	<ul style="list-style-type: none"> • It depends on circumstances • Possibly willing to share finances, mental health data under certain circumstances <p>What do I HAVE to share?? -> TRUST</p>	<ul style="list-style-type: none"> • Context specific information • Easy, secure, accessible 24/7 <p>Medical & care plan</p>	<ul style="list-style-type: none"> • Cloud-based, mobile element • Secure • Real-time data • Alerts • If the situation requires, possibility to gain access to more data <p>Patient data entry</p>

		Generally who is involved in the care of the citizen				
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