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Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for Greater Manchester

CLAHRC Heart Failure Alert Cards

Evaluation Report

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The pilot project reported here would not have been possible without the help and support of a number of people. We would like to thank Manchester community health HF services for giving us the opportunity to pilot the alert cards.

The project would not have been possible without the commitment, hard work and motivation of the South Manchester community HF nurses Margo Megahed and Carolyne Feldman. Thank you also to University Hospital of South Manchester and Simone Reece Advancing quality HF nurse.

Foreword

The idea for the Heart Failure Alert Cards originated from the stakeholder meetings held by the Greater Manchester CLAHRC heart disease implementation theme in 2009.

A consistent problem identified by providers was the lack of communication between community specialist providers and secondary care, specifically when patients were admitted to hospital and discharged home. Many patients were admitted to medical wards for co-morbid problems, but their outcomes and treatment were affected by their underlying heart failure.

Hospital staff often lacked expertise in heart failure, and were uncertain about contacting community specialist providers. A lack of input from community providers about the patient could lead to unnecessary tests, changes in medication, limited community specialist provider input into discharge planning, and lack of timely specialist follow-up after discharge.

Patients and families did not think that hospital staff listened to them about their HF, and families did not always notify community specialist providers regarding admission and discharge. After consideration of a number of ideas and a review of relevant literature, patient held alert cards were put forward as a possible solution. There was some evidence that they could improve continuity of care and empower patients, and a similar card had been tested in another health system. The Heart Failure Alert Card tested here was developed with the input of patients and providers, and we are grateful for their support and assistance.

This evaluation report documents the pilot test of the Heart Failure Alert Card with the help of two community Heart Failure Specialist Nurses, the patients on their caseload, and the Heart Failure Link Nurse and nursing and medical staff at University Hospital of South Manchester NHS Foundation Trust.

In addition to collecting data about patient hospitalisation, communication between hospital and community specialist providers, we also interviewed patients and providers about their experiences using the cards. Our conclusion is that the cards can help to improve communication and continuity of care, and gave patients a sense of empowerment.

We would like to thank the patients, hospital staff, and especially the community Heart Failure Specialist Nurses, Margo Megahed and Carolyne Feldman, for their help in this work. I would also like to thank Lorraine Burey, Knowledge Transfer Associate, for leading this work for GM CLAHRC.

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Executive summary

- A mapping exercise of heart failure (HF) professionals and services undertaken in NHS Manchester during 2009 identified poor communication between primary and secondary care as a problem. In particular community heart failure specialist nurses (HFSN) were not being notified when patients on their caseload were admitted to hospital.
- The impact upon patient care was highlighted as; unnecessary tests requested on admission, unnecessary inpatient referrals to therapists, HFSNs being unaware of medication changes on discharge and lack of specialist input into discharge planning.
- A twelve month project was undertaken by the Collaboration for Leadership in Applied Research and Care (CLAHRC) and the South Manchester community HFSNs to pilot a HF alert card.
- A HF alert card, the size of a credit card was developed with input from patients and public and the HFSNs involved in the pilot.
- The HFSNs treated a total of 160 patients during the period of the pilot of which 119 were issued with alert cards.
- During the pilot there were a total number of 61 admissions (38 patients).
- In 49 of the 61 admissions, the HFSNs were notified of the admission: 30 notifications came from health care professionals (HCP) and 19 from family members.
- The HFSNs received 37% (n=18) notifications from secondary care nurses and 25% (n=12) of notifications from primary care nurses. In the previous 12 months, the HFSNs had not been notified of any admissions by secondary care staff and only occasionally by primary care nurses.
- In two cases the HFSNs were contacted by a hospital outside their catchment area and once by a rehabilitation unit as a direct result of the alert card, which is something that had not previously occurred.
- 97% (n=59) of patients were not admitted onto a specialist cardiology ward. This cohort of patients had previously been identified as being at a higher risk of having their medication changed or stopped. In 79% (n=47) of cases the HFSNs were notified of admission with 36% (n=17) of these notifications coming from secondary care staff.
- In 59% (n=36) cases of cases the HFSNs were informed by secondary care HCPs of their patient being due for discharge. In the twelve months prior to the alert card pilot the nurses had not been contacted by secondary care staff at all to notify them of any patients being due for discharge and considered this to be a significant improvement in communication.
- The HFSNs considered that they were more involved in in-patient care as a result of the alert cards and in some instances were able to discuss cases with secondary care clinicians, provide baseline information about patients and advise on patient management.
- Patients/carers felt they were empowered to take a more active role in their care by showing the alert card and requesting that their HFSN was informed of their admission.
- Patients were asked to show their card when they attended secondary care out-patient appointments. As a result of this the HFSNs have started to be copied into letters that would previously have been sent only to the patients' GPs.
- For some patients being able to show the alert card legitimised the fact that they had HF, as showing the card was considered to make it more official.
- The alert card could be spread to different services, for example, community matrons, active case managers, secondary care HFSNs and General Practitioners. The concept of the alert card would remain the same but the information on the card would need to be revised to reflect the service.
- Regular reinforcement would be required within secondary care to promote the alert card and raise staff awareness of its use. The use of posters, regular emails and reinforcement at staff meetings have all been suggested as mediums to promote the alert cards.

Introduction

HF affects around 900,000 people in the UK and is particularly common among older people, with prevalence expected to increase over the next 20 years[1].

HF can be extremely debilitating and there is evidence that people with this condition have a worse quality of life than those suffering from most other chronic conditions. As a result, HF impacts significantly on the number of emergency admissions and re-admissions to hospital. HF accounts for 2% of NHS inpatient days and 5% of all medical admissions to hospital and is the largest single reason for emergency bed days due to a chronic condition. Rates of re-admission are also among the highest for any of the other common conditions in the United Kingdom.

HF has become a major public health problem in the United Kingdom. The British Heart Foundation estimates that there are about 68,000 new cases of HF each year[2]. A survey of HF care by primary care physicians in Europe found that only 20% of doctors in primary care prescribed the recommended treatment of ACE inhibitors and beta blockers in combination, and dosages were 50% of guideline recommended targets[3]. Knowledge and treatment delivered were inconsistent, suggesting the need for improved links between secondary and primary care. A survey of acute HF hospital admissions in England, Wales and Northern Ireland showed that less than 20% of people were followed by a specialist service after discharge despite evidence that this improves outcome and resource utilisation.

Many of the instances of poor quality care can be linked to problems that arise at the interface between different healthcare systems[4]. Organisations tend to focus upon their own resources and perspective rather than viewing the system as a whole, which is how it is actually experienced by the patient. There is a need to improve the quality of communication between different organisations; however, the complexity of the task can result in uncertainty about whose responsibility this actually is.

There is very little in the literature about the use of medical alert cards to ensure continuity of care. Their use is mainly to alert HCPs of a pre-existing condition, for example, diabetes, anticoagulation, chronic respiratory disease and not to promote communication between primary and secondary card[5].

1 Health Care Commission (2007) *Pushing the Boundaries: Improving Services for People with Heart Failure*, HCC, London

2 British Heart Foundation (2009) *Heartstats: Numbers dying from CVD and CHD (online).* Available from www.heartstats.org/dtatpage.asp?id=713

3 Komajda M, Follath F, Swedberg K. (2003) *The Euro Heart Failure Survey programme - a survey on the quality of care among patients with heart failure in Europe*. Part 2: treatment. European Heart Journal; 24: 464-474.

4 Kvamme O.J., Olesen F., Samuelsson M., (2001) *Improving the interface between primary and secondary care: a statement from the European Working Party on Quality in Family Practice(EQuiP), Quality in Healthcare*, 10 pp 33-39

5 Goopta B., Ward L., Ansari S.O., Eraut C.D., Law D., Davison A.G. (2006) *Oxygen alert cards and controlled oxygen: preventing emergency admissions at risk of hypercapnic acidosis receiving high inspired oxygen concentrations in ambulances and A&E departments*, Emergency Medicine 23 pp 636-638

Background

An exercise was undertaken within NHS Manchester during 2009 to gain an overview of and map existing HF pathways and services. Interviews were conducted with a selection of HCPs from both primary and secondary care involved in the treatment of people with HF to elicit their views on how services and processes might be improved.

The findings from the scoping exercise were presented to all stakeholders and a common consensus was reached to develop a NHS Manchester Standard of HF Care. The HF alert cards were identified as one tool that could be developed and tested in order to improve communications at transitions of care between primary and secondary care services.

A lack of effective communication between health care professionals involved in the care of HF patients was identified by all participants in the mapping exercise. In particular HFSN and community matrons (CM) raised concerns that they were not notified when patients on their case load were admitted to hospital and discharged home, whilst ward staff reported that they were unsure who to contact and what services were available in the community. The impact upon patient care was highlighted as; unnecessary tests requested on admission, unnecessary inpatient referrals to therapists, HFSNs and CMs unaware of medication changes on discharge and lack of specialist input into discharge planning.

Two HFSNs from the south sector of Manchester agreed to pilot the alert card. They reported an existing lack of communication between primary and secondary care and that if they were informed of a patient being admitted to hospital it was by the patient's family or occasionally by the district nurse. It was not possible to use an electronic flagging system to identify patients and it was considered that using an alert card would be more empowering to patients rather than being totally dependent upon health care providers.

It was anticipated that the alert card would be of particular benefit for patients who were admitted onto non-specialist wards; in particular general medical wards with a non-cardiology diagnosis, for example, chest infection and urinary tract infection. According to the HFSNs it was this cohort of patients who were more likely to have their medication changed or stopped, as they would be under the care of non-specialist clinicians. Notification of patient discharge was also identified as a problem area. The HFSNs wanted to improve this situation by raising awareness of their involvement in patient management and considered that piloting the alert cards would be a useful exercise.

During the pilot the average caseload size was 100 patients. The total number of patients seen was 160. Of these 51% were female and 49% male, all patients were over the age of 40 with 50% of patients in the over 80 year old age bands. Patients on the caseload had an average of 3 co-morbidities, with chronic kidney disease the most prevalent.

NHS Manchester is divided into three distinct sectors and the alert card was piloted using the case load of a community HF nursing service in the south sector. The resident population of Manchester is 483,831 with 156,359 residing in the south sector of the city[6]. The ethnicity breakdown of the south sector is 86.6% all white groups compared with 76.5% for the whole of Manchester. The deprivation score for the south sector is 36.79 and 41.13 for Manchester as a whole (the higher the score indicates the more deprived the area). However, within the different wards of the south sector there is a significant variation in scores ranging from 16.37 to 50.02.

During the pilot study, a part-time secondary care HF link nurse was employed and it is possible that this new role may have had some influence on the success of the cards, as part of the link nurse role was also to identify HF patients.

6 Public Health Manchester Intelligence Team (2011) *A Picture of Progress: Compendium of Statistics 2011*, Manchester City Council; Manchester

Aim

The overall aim for implementing the HF alert cards pilot was to improve communication between HCPs thereby improving the information handover on admission and discharge from hospital.

Objectives

The objectives are as follows:

- To ensure important baseline information is communicated to staff in secondary care to eliminate inappropriate referrals to other services.
- To empower patients to take an active role in their care by identifying that they have a specialist nurse.
- To increase the instance of HFSNs being notified by a HCP that a patient on their caseload has been admitted to hospital.
- To Increase the instance of HFSNs being notified that a patient on their caseload is due to be discharged home or to other facility.

Project Design

A HF alert card was developed to be distributed to all appropriate patients on a HFSNs caseload for a period of twelve months from September 2010 to September 2011. The HFSNs made a clinical judgement when issuing cards and excluded those patients who were cognitively impaired or very elderly or frail.

Building the advancing quality work North Cumbria University Hospital Foundation Trust three patient and public involvement events were held throughout NHS Manchester where the alert card was presented and received positive feedback. The HFSNs participating in the project and patients and public were also involved in the final design of the card.

The card is the size of a credit card and contains patient information, the most recent echocardiogram (ECHO) result, details of the patient's general practitioner (GP) and the HFSNs contact details (see appendix l). It was designed to fit into a wallet or purse so it would be more likely to be available if a person was admitted to hospital as an emergency.

The alert card was intended to be issued by the HFSNs during face to face clinic appointments or when performing a home visit. However, in a small number of cases where this was not possible the card was issued by post. Each card was issued with an explanatory leaflet (see appendix 2) and the information was also reinforced verbally by the nurses. Patients were asked to present this card if admitted to hospital and request that staff contact their HFSN to inform them that they have been admitted. All patients were also asked if they would be willing to participate in a telephone interview at the end of the pilot.

The HFSNs treated a total of 160 patients during the period of the pilot of which 55% were female and 45% male; 119 were issued with cards.

Quantitative data on hospital admissions was collected throughout the twelve month period by the HFSNs involved in the project. The data was collated onto a spreadsheet and the information documented as follows:

- Gender
- Hospital of admission
- HFSNs informed of admission
- Person who informed them
- Reason for admission
- HFSNs informed of discharge

In the twelve month period prior to the project the HFSNs had a total of 103 admissions (63 patients) and had not been contacted at all by secondary care nurses to advise them that any of their patients had been admitted or discharged from hospital.

Qualitative data was collected using a purposeful convenience sample. This sample consisted of, a secondary care HF link nurse, the two HFSNs involved in the pilot, three patients and one carer. Semi-structured interview schedules were developed for the HCP and patient/carers (see appendix 2).

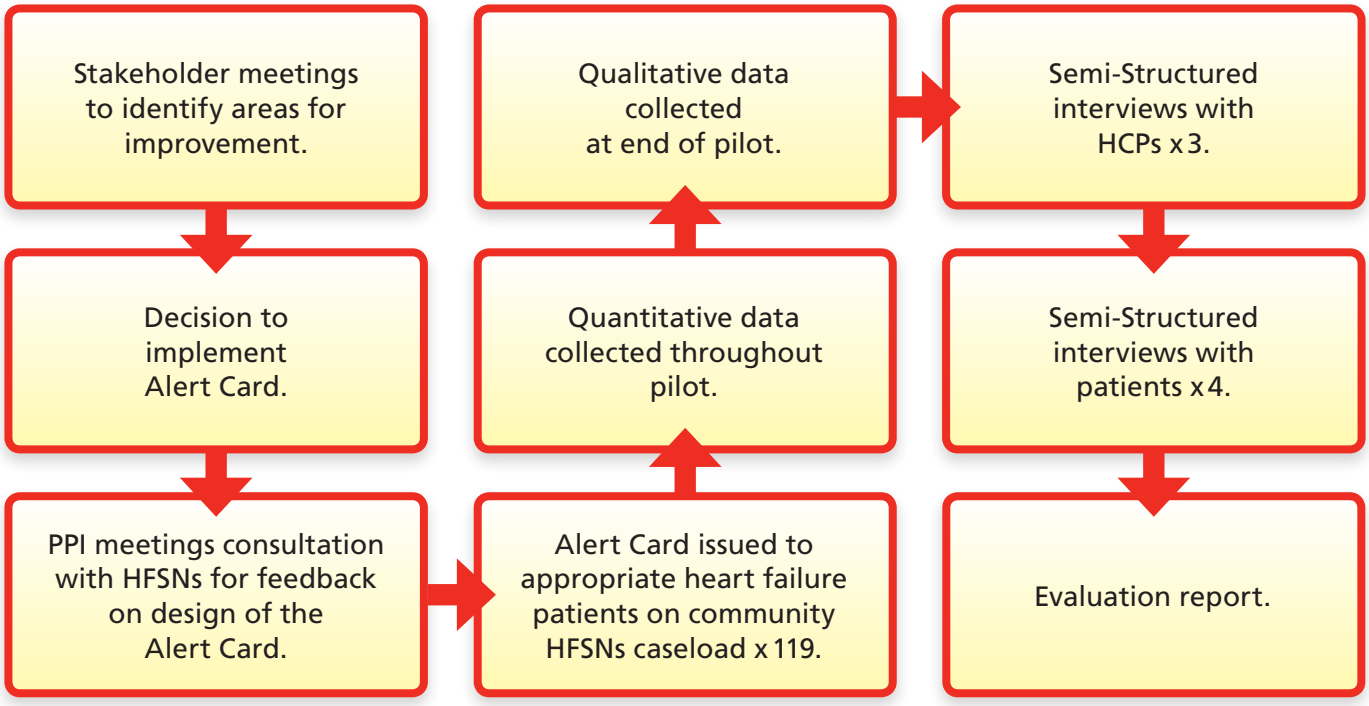
The HFSNs used their clinical judgement to select patients to interview and made the initial contact. Verbal consent was obtained and semi-structured telephone interviews were conducted, all interviews were recorded and transcribed.

Quantitative Measures

- Measure the number of times staff in HCPs contact the HFSNs as to inform patient admission as a result of the alert card.
- Measure the number of times HFSNs are notified that a patient is being discharged.
- Measure who contacts the HFSNs

Qualitative Measures

- Conduct telephone interviews with patients for their views and experience of using the card.
- Conduct telephone interviews with the HCPs involved in the project to ascertain their views of the alert card.



Quantitative results

- During the 12 month period from September 2010 there were a total of 61 hospital admissions (38 patients in total).
- Over the 12 month period of the pilot there were a total of 160 patients on the HFSNs caseload of which 74% (n=119) were issued alert cards.
- The majority of patients were admitted for conditions other than HF, only 11% (n=7) were admitted due to HF.
- 59 hospital admissions were unscheduled and 2 admissions were elective.

Fig 2 - **Was the CHFSN Informed of Admission?**

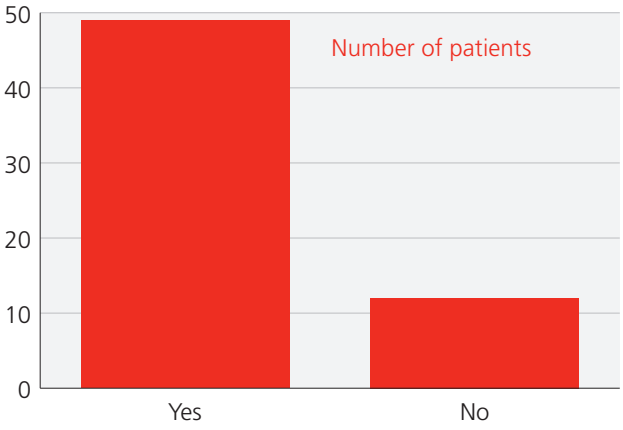


Figure 2 shows that in 80% (n=49) cases the HFSNs were informed that a patient on their case load had been admitted to hospital. According to the HFSNs this represents a large increase in the number of times they were notified in the previous 12 months.

Fig 3 - **Who Alerted the CHFSNs?**

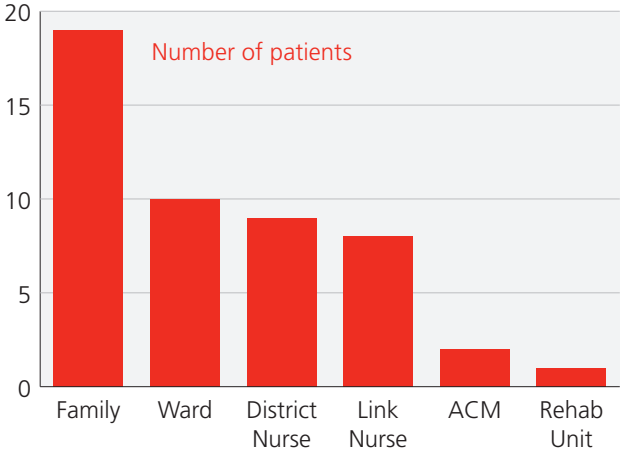
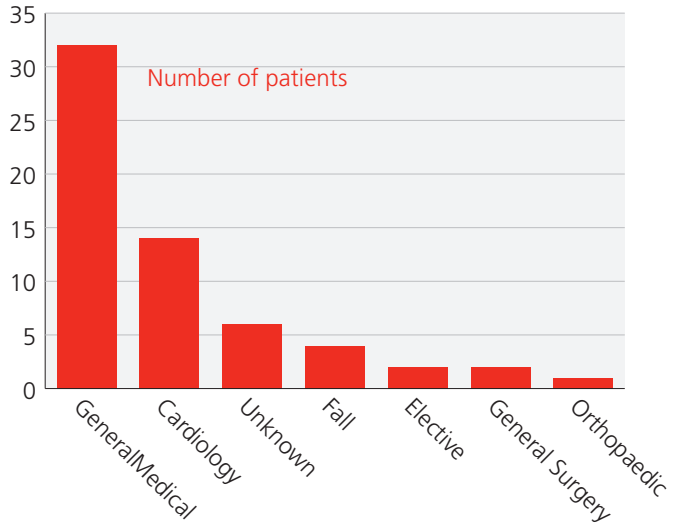


Figure 3 shows a breakdown of the 49 cases (out of 61 admissions) where the HFSNs were contacted to inform them of patient admission. Overall, 61% (n=30) notifications came from HCPs and 39% (n=19) from family members.

Of the 49 cases where the HFSNs were contacted they received 37% (n=18) of notifications from secondary care nurses. In the previous 12 months, the HFSNs had received no notifications of admission by secondary care staff thus representing a significant increase. 25% (n=12) of notifications were from primary care nurses and 38% (n=19) notifications were from family members.

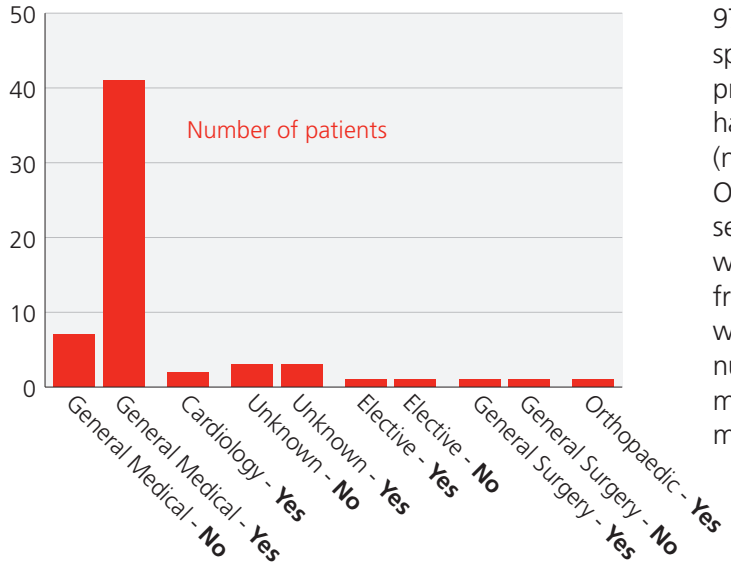
In two cases the HFSNs were contacted by a hospital outside their catchment area and once by a rehabilitation unit as a direct result of the alert card, this is something that had not previously occurred.

Fig 4 - **Reason for Admission**



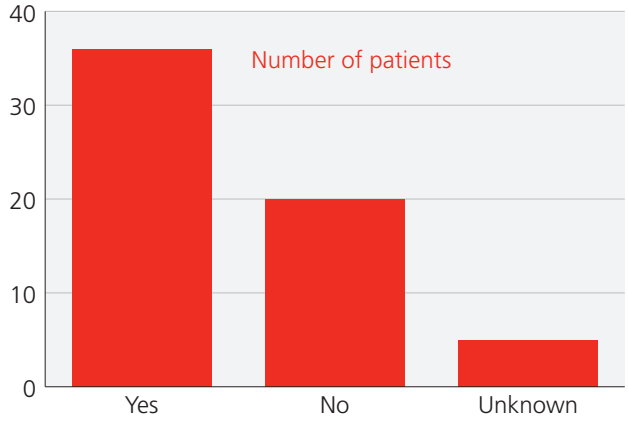
In figure 4 the reason for admission has been categorised as general medical, surgery, orthopaedic etc. Only 2 patients were admitted to a cardiology ward, the majority were admitted to a general medical ward.

Fig 5 - **CHFSNS Informed of Admission by Speciality**



97% (n=59) of patients were not admitted onto a specialist cardiology ward, this cohort of patients had previously been identified as being at a higher risk of having their medication changed or stopped. In 79% (n=47) of cases the HFSNs were notified of admission. Overall 36% (n=17) of these notifications came from secondary care staff. Of the 47 cases where the HFSNs were contacted they received 19% (n=9) notifications from a district nurse, 21% (n=10) notifications from ward staff, 14% (n=7) notifications from the HF link nurse, 4% (n=2) notification from an active case manager and 23% (n=19) notifications by a family member.

Fig 6 - **Informed of Discharge**



In 59% (n=36) of cases the HFSNs were informed by secondary care HCPs of their patient being due for discharge. This represents a significant improvement as in the twelve months prior to the implementation of the alert card the HFSNs had received zero notifications from secondary care.

The improvement was especially important in patient admission to non-cardiology wards, where nurses were less knowledgeable about HF and changes in treatment were more likely to occur. (Patients admitted to these wards have multiple co-morbid conditions and are likely to be admitted for other causes)

Qualitative Results - Practitioners

Three main themes emerged from the interviews with the HCPs in relation to communication, patient empowerment and diagnosis.

Communication

First impressions

All HCPs interviewed considered piloting the alert card to be a good idea. An existing lack of communication between primary and secondary care had been identified during an initial scoping exercise and the alert card was viewed as something that could possibly begin to help to facilitate communication between the two organisations:

"When the idea was first raised I thought it was quite a good idea because there were, we recognised that there was a lack of communication through secondary and primary care and we thought it might facilitate better communication really across the two and improve the discharge for patients..." (HCP3)

"We were prepared to try anything really because it clearly was a bit of a nightmare for us. It's embarrassing when we go out to a patient and they say 'well of course I've been in hospital' and you wonder when all their tablets are completely different to when you last saw them. So there's been a big communication problem which we hoped the HF alert cards would help alert someone to our involvement" (HCP 2)

"I thought it was a good idea, you know, anything that raises the awareness of patients that are already known. So I thought it was a good idea" (HCP 1)

It was highlighted that patients do not always understand how the healthcare system works and presume that everyone involved in their care communicates with each other and that the HFSNs would automatically be notified if they were admitted to hospital.

Issuing the alert cards to patients provided the nurses with the opportunity to explain to them that this is not always the case and to reinforce the importance of showing the alert card if they are admitted to hospital so that they could be informed of their admission:

"I go through it with them, I tell them, I say to them 'keep this with you. If you go into hospital for any treatment at all and they change your tablets or you've been admitted, you need to show them this card and you need to let us know'. So even if the card doesn't initiate somebody, they understand that someone needs to tell us." (HCP2)

Improvements in Communication

The HCPs interviewed considered that communication with secondary care had improved significantly since the introduction of the alert cards. During the pilot a part-time secondary care HF link nurse was employed and it is recognised that this new role had some influence upon the success of the cards, as the link nurse reinforced the use of the cards within the hospital and as part of her role also identified patients with HF and contacted the HFSNs to advise them of admissions:

"The family and patients were already quite good, from the hospital itself we receive phone calls from the link nurse and also directly from the ward as a result of the card being shown." (HCP3)

"It certainly has increased since we started doing the alert card on I would say the majority of admissions we receive either notification from the xxxx, which is the link nurse and she is also aware of the card or directly from the ward." (HCP 3)

An additional unanticipated benefit was that patient admissions were notified to the HF link nurse:

"It lets them (ward staff) know that they're HF and they can perhaps contact me. They (ward staff) don't have to do anything else other than a quick phone call because I see all the inpatients you see. So I think it's advantageous just in general really so that people are aware that person's been diagnosed with HF." (HCP 1)

The card was also successful on occasions when patients were admitted to other hospitals outside the catchment area of the HFSNs. They were notified of admissions by another local hospital and also from different parts of the country when patients were admitted when on holiday:

"I've had one or two patients admitted into hospital as a result of a fall but in a different part of the country and they've produced the card and we were contacted by the hospital. So that has certainly happened on two occasions with my patients where they were admitted into other district hospitals." (HCP 3)

Families/Carers

The process of issuing the alert card and the accompanying education provided by the HFSNs was considered to give families and carers more 'permission' to contact them. This was particularly relevant to new patients as those who had been on the caseload for a longer period had received regular encouragement to contact them.

"I think it gives them (families/carers) permission, we always give them permission and actively encourage them to call us if they're not sure and in fact to be fair a lot of the alerts come from the family and the alert card is a reminder to them that they are not to forget that even if it's not anything to do with their heart, they need to get in touch with us. So it's quite successful in that sense that often it's not the ward that alerts us, it's the family. As soon as they're in, we get a phone call from the family and I think the card's played a part in that because prior to the card that didn't happen, even though we asked them to." (HCP 2)

"Maybe it gave the new patients more permission… if they had concerns about a relative they would ring for advice. So from that point of view yeah. For patients that are long standing… that was part of the management we do, we encourage families, but maybe it gave them a bit of ownership and a bit of being able to say there is a problem here… it kind of makes it easier in some ways."(HCP3)

Patient Management

The HFSNs have also become more involved in the management of their patients during their hospital stay. The improvement in communication has been evident in primary and secondary care since the introduction of the alert cards the HFSNs have become more proactive in contacting the hospital and consider that they have started to build relationships, for example, receiving telephone calls from secondary care clinicians in relation to patient management which had not previously occurred.

"I think for me, my experience has been that it's meant that when I've been informed I can then ring and discuss it with the doctors. I used to just ring the wards and ask them to tell me when the patient was going home but I know the nurses how busy they are on the ward and I don't know how much of that gets conveyed. So I now automatically speak to the SHO (senior house officer) as the person looking after them. Also that's the chance to determine some of the decision making." (HCP 2)

"We have had better communication from the hospital and certainly changes would be made in medication on some occasions we were able to highlight to the staff that a particular patient needed quite a high dose of diuretic or to make sure that they were restarted on a beta-blocker if it had been stopped. So it has definitely improved it." (HCP 3)

"I certainly have had phone calls from registrars in the hospital to say this patient is under your care and there were some issues around medication and I've discussed it, particularly the high risk patients, on very, very, high doses of medication that we don't want to dramatically reduce..." (HCP 3)

Other Improvements in Communication

The alert card was developed and piloted with the main aim of improving communication between primary and secondary care in relation to patient admission as the community HFSNs were not being contacted when their patients were admitted to hospital. However, during the pilot it was revealed that the card also had other uses.

As an emergency card:

"if a patient's admitted to hospital or they collapse on the street they have the card in their wallet it automatically tells A&E staff when they check their belongings that the person has got HF and that's the main thing." (HCP 3)

Sharing information:

"A lot of GPs don't have access to echocardiogram results so although patients have an ECHO they don't have any results, they don't know when the ECHO was done so on the card itself it states the date of the last ECHO and it also states the ejection fraction. So from that point of view I think the GPs might like it." (HCP 3)

"When the ward informs us of the discharge ...we then can chase up the doctors who are looking after the person and track them down and actually offer and share information in that sense, like perhaps we'll send them a community ECHO instead of them repeating a hospital one...or sharing of information about a person's cognitive behaviour of compliance issues." (HCP 2)

Patients were also asked to show their card when they attended out-patient appointments alerting the secondary care clinician that they were under the care of the community HFSNs. As a result of this the nurses have started to be copied into letters that would previously have been sent only to the GP. Additionally the card has been used successfully in different setting and the nurses have been contacted by intermediate care and respite care facilities to notify them of patient admissions.

One patient was referred to A&E by the out of hour's service seven times due to high potassium blood levels. On the first two occasions they were admitted and repeat bloods taken the following day which were normal.

However, as this condition was known to their GP and the HFSNs on the subsequent five occasions they showed their HF alert card and assured A&E staff that they would be followed up by their HFSN and were allowed home for primary care follow up avoiding being admitted as an emergency.

Patient empowerment

Effective management of chronic diseases in primary care involves a number of key elements. These include; disease registers, effective prescribing and medicine management, and the enabling of self-care and patient empowerment[7]. Feedback from patients has been positive and feedback to the nurses suggests an element of patients feeling more empowered.

"They love it. They love it. They know that it's their security. They have the contact details on there so if they are admitted into hospital or they go for a consultation with a doctor they have started producing the card, saying listen this is what I've got." (HCP 3)

"...I think it depends on the patients themselves. If it's a patient that's in the position to be involved in their own care then it empowers them doesn't it because it's a way of them saying 'look, this is part of my care that you should take into consideration.' But not all patients fit into that category." (HCP 1)

"There is an element that patients have confidence, so it becomes a sort of a comfort blanket having it there." (HCP 2)

7 Department of Health (2002) *Chronic Disease Management and Self Care: National Service Framework*; DOH; London

"…particularly if they have been in hospital previously and we didn't get contact that they'd been admitted or that they'd been discharged and medication had been changed previously. So it did improve that and they (patients) certainly like to have that because in a way it makes them, it's easier for them to say 'well I have this condition.'" (HCP 3)

Diagnosis

HF is a serious condition with a poor prognosis and it is unclear if patients suffering from HF actually appreciate the seriousness of their condition[8]. Clinicians may sometimes be reluctant to inform patients of their prognosis unless directly asked about it. Many HF patients are elderly and may find the information given to them at the time of diagnosis difficult to understand[9]. Although the HFSNs explain and discuss the diagnosis of HF to their patients as part of their assessment they found that in some cases the card prompted patients to ask questions about their condition.

"They've all been very accepting and OK. I've never had anybody excited about the thought that they've got the card but I have had a few that have wanted to know what things meant on the card, particularly when it says severe LVSD (left ventricular systolic dysfunction)." (HCP 2)

"It makes it (diagnosis) more real and that's certainly the feedback from the patients." (HCP 3)

"I give them the card and then because the first, it usually takes an hour the first visit and I will be filling in bits and pieces and I will start by saying 'I'm going to start by giving you this card and explain what it is. You have a look on it to see if there's anything you don't understand' while I'm filling in demographics from their admission sheet. And then they'll say 'what's this and what's that?' But that's usually our opportunity as it leads me in to explaining what HF is and why things go wrong with the heart." (HCP 2)

8 Allen LA, Yager JE, Funk MJ et al. (2008) *Discordance between patient-predicted and model-predicted life expectancy among ambulatory patients with heart failure.* JAMA;299:2533-42

9 Banerjee P, Gill L, Muir V, Nadar S, Raja Y, Goyal D, Koganti S (2010) *Do heart failure patients understand their diagnosis or want to know their prognosis? Heart failure from a patient's perspective*, Journal of the Royal College of Physicians; 10; (4); pp 339-343

Qualitative Results - Patients

A total of three patients and one carer were interviewed by telephone. The patients and carer were identified and initially contacted by the HFSNs. All interviews were taped and transcribed; the main themes to emerge were in relation to using the alert card, patient/carer's views of the card and empowerment. In three cases the card was issued during a face to face consultation and in one case it was posted along with an explanatory leaflet. Themes to emerge were patient/carers views, use of the card and empowerment.

Patient/Carer Views

All Patients/carers interviewed considered that the alert card was a good idea and their initial thoughts when issued with the card were positive.

"Well I wasn't aware of them of course naturally enough because they'd only just started but it didn't even cross my mind about it, you know, but I did think it was a good idea because they could be treating me for something and ignoring the fact I'd got HF if they didn't know about it and maybe start some tablets that they shouldn't because that has happened" (P/C 1)

"Yeh it's good really I think it's quite good" (P/C 3)

"Personally I thought it was a good idea, that your information is available to all. When I went into hospital it took quite a long time to diagnose what was wrong with me… so on that basis I think it's a good idea" (P/C 2)

The symptoms of HF can vary widely between individuals. Additionally, all patients interviewed were under the care of community HF specialist nurses which according to the British Heart Foundation improves symptom control, increases survival rates and improves the health related quality of life for both patients and carers[10].

"Well some people look very well and you wouldn't think to look at them that there was anything the matter with them because I know a couple of people that have had HF look better than I did and there was nothing wrong with me then. It affects people differently." (P/C 1)

"…If anybody looks at me they don't think there's anything wrong with me. I don't look ill." (P/C 2)

"…it lets people know that you're not as you look." (P/C 1)

Therefore being able to show the alert card, for some patients, legitimised the fact that they had HF, as showing a card was considered to be more official than verbally communicating their condition.

"It was just that I feel more confident with it now because it's better than me saying to them 'look I've got HF'. It feels better handing them a card. It's more official looking" (P/C 1)

"…It's good to have it and the information is available by phone call… I think it's brilliant." (P/C 2)

Using the Alert Card

When issuing the cards the HFSNs explained the purpose of the card and how to use it, for the person who received their card by post a leaflet was enclosed explaining how to use it.

"Well she explained that it was a pilot and asked me if any time I was admitted to the hospital, if I would show it to them so that she was notified." (P/C 1)

"It came through the post it was quite clear what it was for." (P/C 4)

10 University of York (2008) *Heart failure nurses services in England*; London; British Heart Foundation

Patients/carers kept the alert card in a wallet, purse or glasses case so it was easily available to show if required. The three patients issued with the card during a face to face clinic appointment showed their card if admitted to hospital or at any out-patient appointments as this had been reinforced by the HFSNs.

"So we can show for any medical things anything he has done it's to show people that he has got HF and everything." (P/C 3)

"Well I'm going to need my glasses if I'm reading, so I knew if I had to look at something and it's always in the pocket of me handbag where I see it all the time. I leave the card coming out just a little back, you know, with the edging, so I can see it, so it kind of jumps out at you because of the colour. So I do, it reminds me then to show it. So I just take it out and keep it in me hand until I show it to somebody and then put it away again." (P/C 1)

"Oh, I'll always carry the card." (P/C 2)

"If you go on holiday and a problem occurs, it's there isn't it and it's a way of finding information out about me…I think it's nice that they can access information about me if unfortunately I did take ill you know." (P/C 2)

However, for the patient who received their card by post, where its purpose had not been reinforced by the HFSN, it was used differently. Although they carried the card in their wallet they stated that they would only show the card if admitted or at an out-patient appointment if asked for it or questioned about it. Their perception of the purpose of the card was for use in only in emergencies.

"Well if it ever occurs this is why I carry it around you know, because it is in a wallet a plastic wallet and I have got my name and address on there so if I am ever in a condition and not able to answer any questions they know exactly where I am and what it's about." (P/C 4)

Patient empowerment

There is much debate about how to define the concept of patient empowerment; however, at the very least it involves a re-distribution of power between patient and clinician [11]. Patients have reported feeling in 'limbo' when moving from one part of the healthcare system to another, referring to this as; a feeling of being unimportant and insignificant, powerless and losing control over what is happening [12]. During the alert card pilot patients were actively encouraged to inform the HCPs in secondary care that they had a HFSN and ask that they contact them something that they had not previously done. Patients considered that the card provided the means by which to do this.

"I am quite confident about it. I think it's (alert card) like a protection for me as well, you know, letting them know. I look at it from the point of view that they're very busy they may not be giving you quite the same attention and I don't mean anything by that just that they're busy and might forget to say something. So if I show the card I'm letting them know." (P/C 1)

"If my tablets were changed I would be showing them the card and saying that is what my medication lists are, so obviously I would want to know, assuming I was fit enough to question them. If not I think my wife would be doing why they were changing something I've been on now at this level for probably nine months." (P/C 2)

"On one occasion one of the nurses said to me that she wouldn't be able to contact her (HFSN) because there was no number on it and I said yeah there is a number on it cause I just felt she didn't read it carefully." (P/C 1)

11 Roberts K. J. (1999) *Patient Empowerment in the United States: A Critical Commentary*, Health Expectations, 2 (2) pp 82-92

12 Preston C., Cheater F., Baker R., Hearnshaw H., (1999) *Left in 'limbo': patients views on care across the primary secondary care interface*, Quality in Healthcare, 8 pp 16-21

Conclusions

The alert card pilot achieved the objectives in terms of:

- There was an increase in the number of occasions the HFSNs were notified of patient admissions to secondary care.
- HFSNs were more involved in in-patient care and able to discuss certain cases with secondary care clinicians and provide baseline information about patients and advice on patient management.
- There was an increase in the number of occasions the HFSNs were informed of patient discharge.
- Patients/carers were empowered to take a more active role in their care by showing the alert card and requesting that their HFSN was informed of their admission.

Recommendations

- The alert card could be spread to different services, for example, community matrons, active case managers, secondary care HFSNs and General Practitioners. The concept of the alert card would remain the same but the information on the card would need to be revised to reflect the service.
- Regular reinforcement would be required within secondary care to promote the alert card and raise staff awareness of its use. The use of posters, regular emails and attendance at staff meetings have all been suggested as mediums to promote the alert cards.
- The identification of someone within secondary care that could promote the use of the card.
- It is recommended that the alert card is issued in person providing the opportunity to discuss the content of the card and how it should be used. The need for patients to show the alert card should be regularly reinforced with patients and carers during clinic or home consultations with details of when to show it.

Appendix 1

HEART FAILURE ALERT CARD

NHS Manchester
Manchester Community Health

THIS PERSON HAS HEART FAILURE

FULL NAME:

NHS NUMBER:

Show this card at all medical appointments including hospital admissions

DATE OF LAST ECHO:

EJECTION FRACTION:

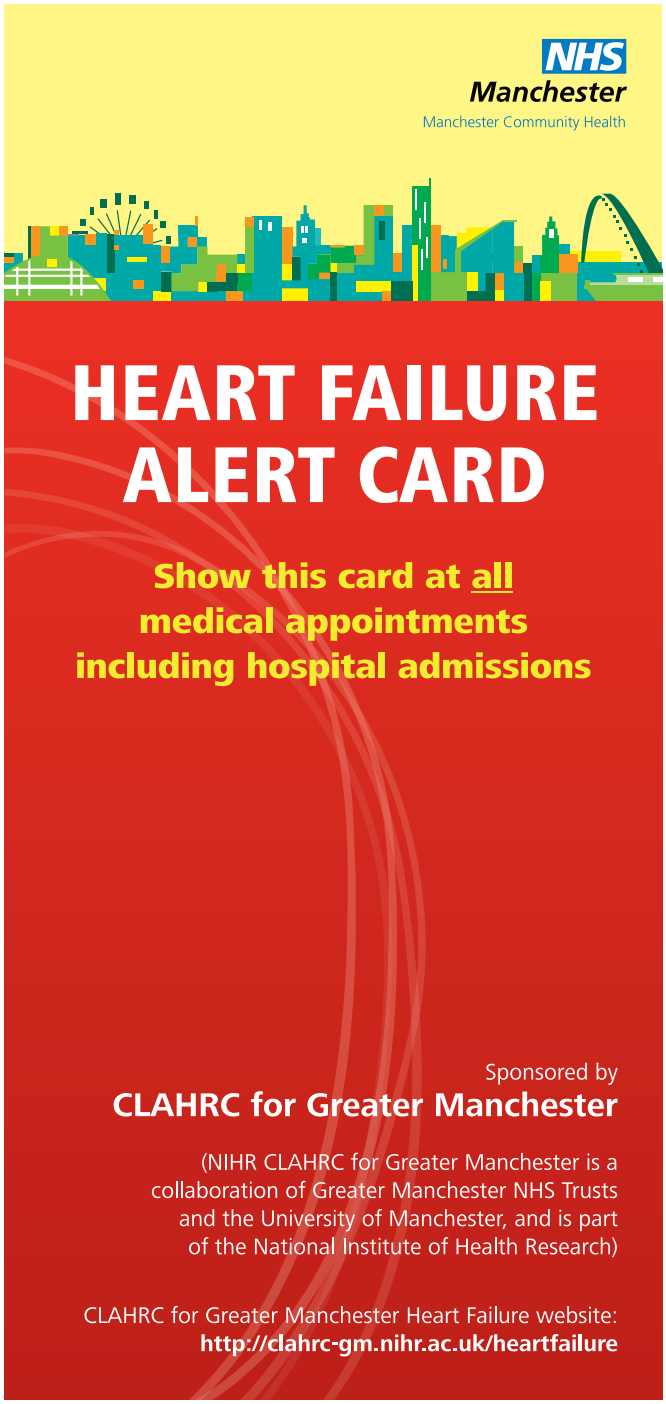
LV FUNCTION:

IN CASE OF HOSPITAL ADMISSION PLEASE CONTACT:

Margo Megahed or Carolyne Feldman
(Community Heart Failure Nurse Specialists) TEL: 0161 435 3518

GP:

Appendix 2



NHS
Manchester
Manchester Community Health

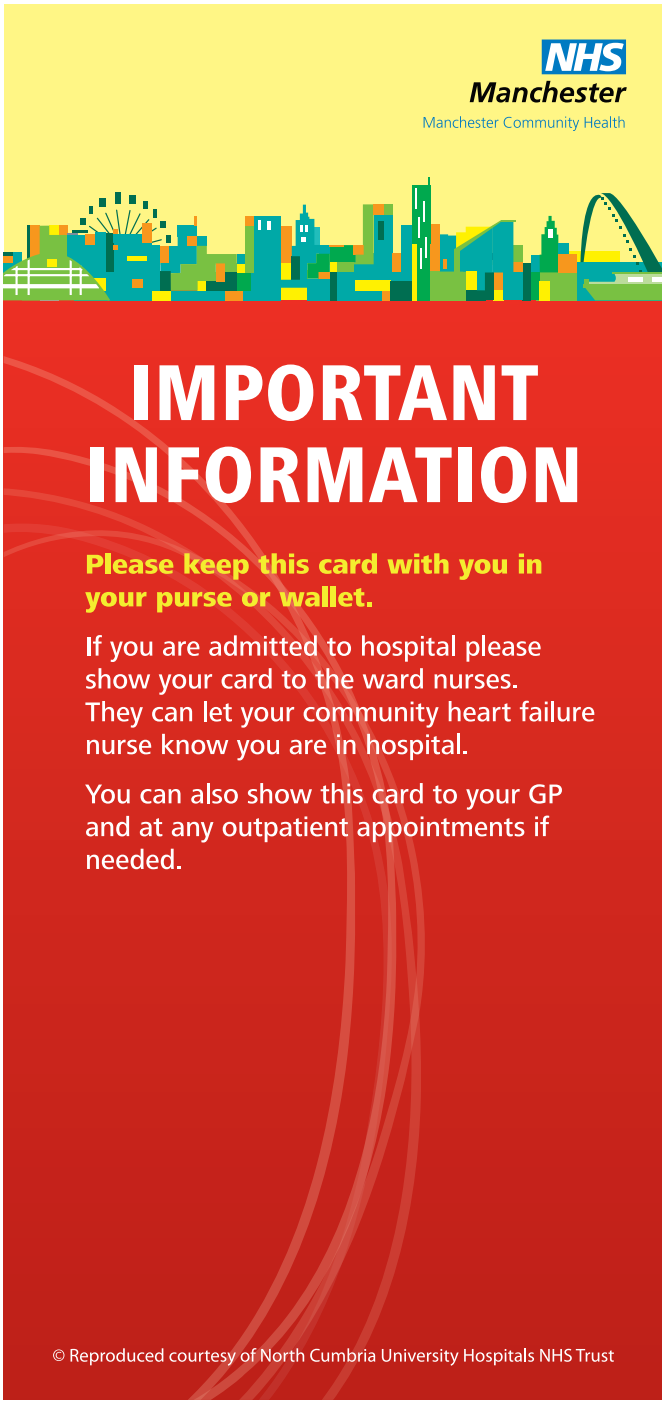
HEART FAILURE ALERT CARD

Show this card at all medical appointments including hospital admissions

Sponsored by
CLAHRC for Greater Manchester

(NIHR CLAHRC for Greater Manchester is a collaboration of Greater Manchester NHS Trusts and the University of Manchester, and is part of the National Institute of Health Research)

CLAHRC for Greater Manchester Heart Failure website:
http://clahrc-gm.nihr.ac.uk/heartfailure



NHS
Manchester
Manchester Community Health

IMPORTANT INFORMATION

Please keep this card with you in your purse or wallet.

If you are admitted to hospital please show your card to the ward nurses. They can let your community heart failure nurse know you are in hospital.

You can also show this card to your GP and at any outpatient appointments if needed.

The Collaboration for Leadership in Applied Health Research and Care for Greater Manchester is a partnership between the Greater Manchester NHS Trusts and the University of Manchester and is part of the National Institute for Health Research.

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