

# Designing an internationally grounded one-stop website for local heart failure patients, carers and service providers

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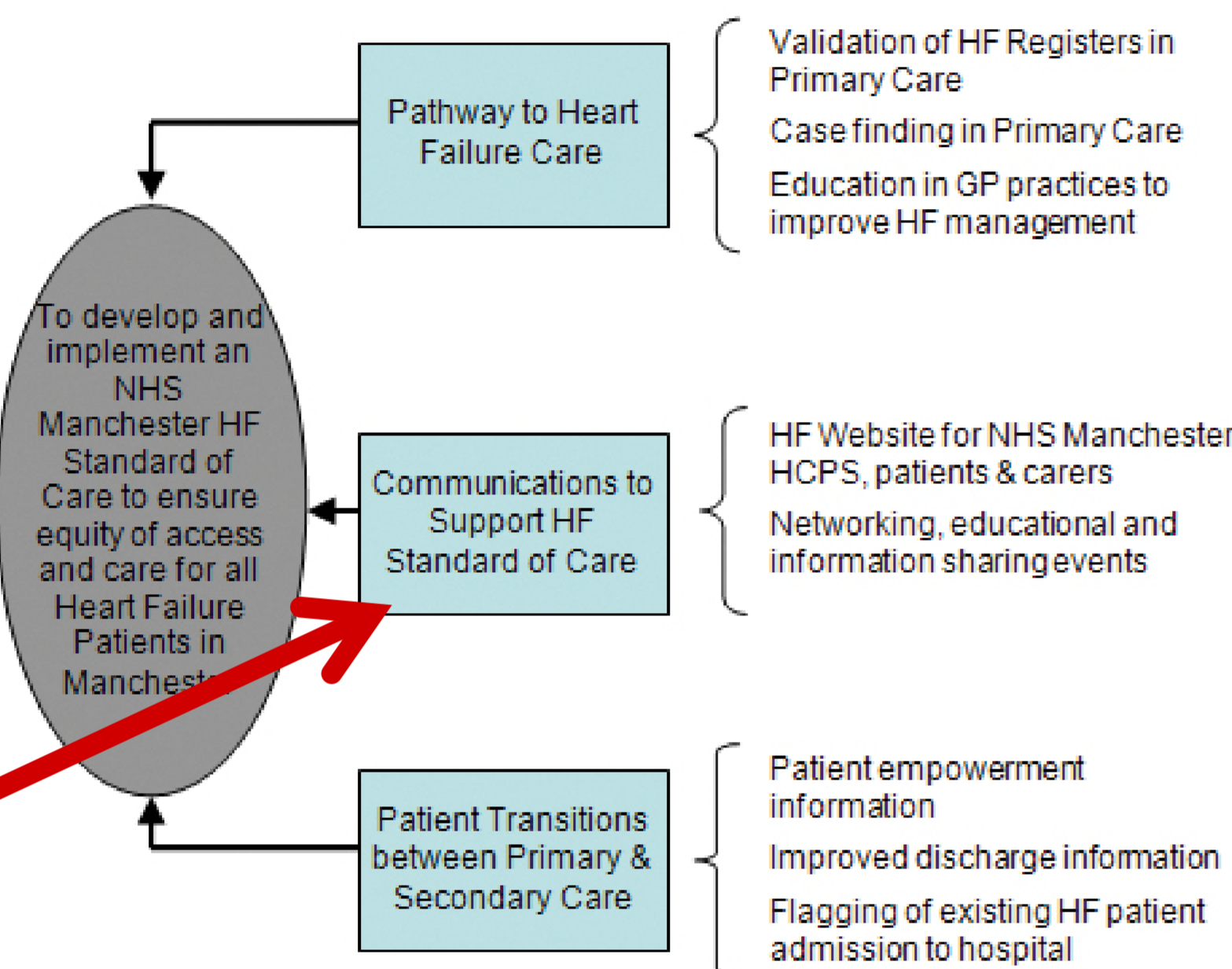
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## Purpose:

Guidelines recommend co-ordinated, multi-professional management of care for patients with heart failure (HF) and systematic reviews support programmes of care which include acute inpatient phases and discharge planning<sup>1</sup>.

The purpose of 'designing an internationally grounded one-stop website for local heart failure patients, carers and service providers', was to improve co-ordination and communication among providers (HCPs) and awareness of available HF services.

Figure 1. Driver Diagram



The GM CLAHRC Manchester Heart Failure website was designed to address four key questions around the issue of 'communication':

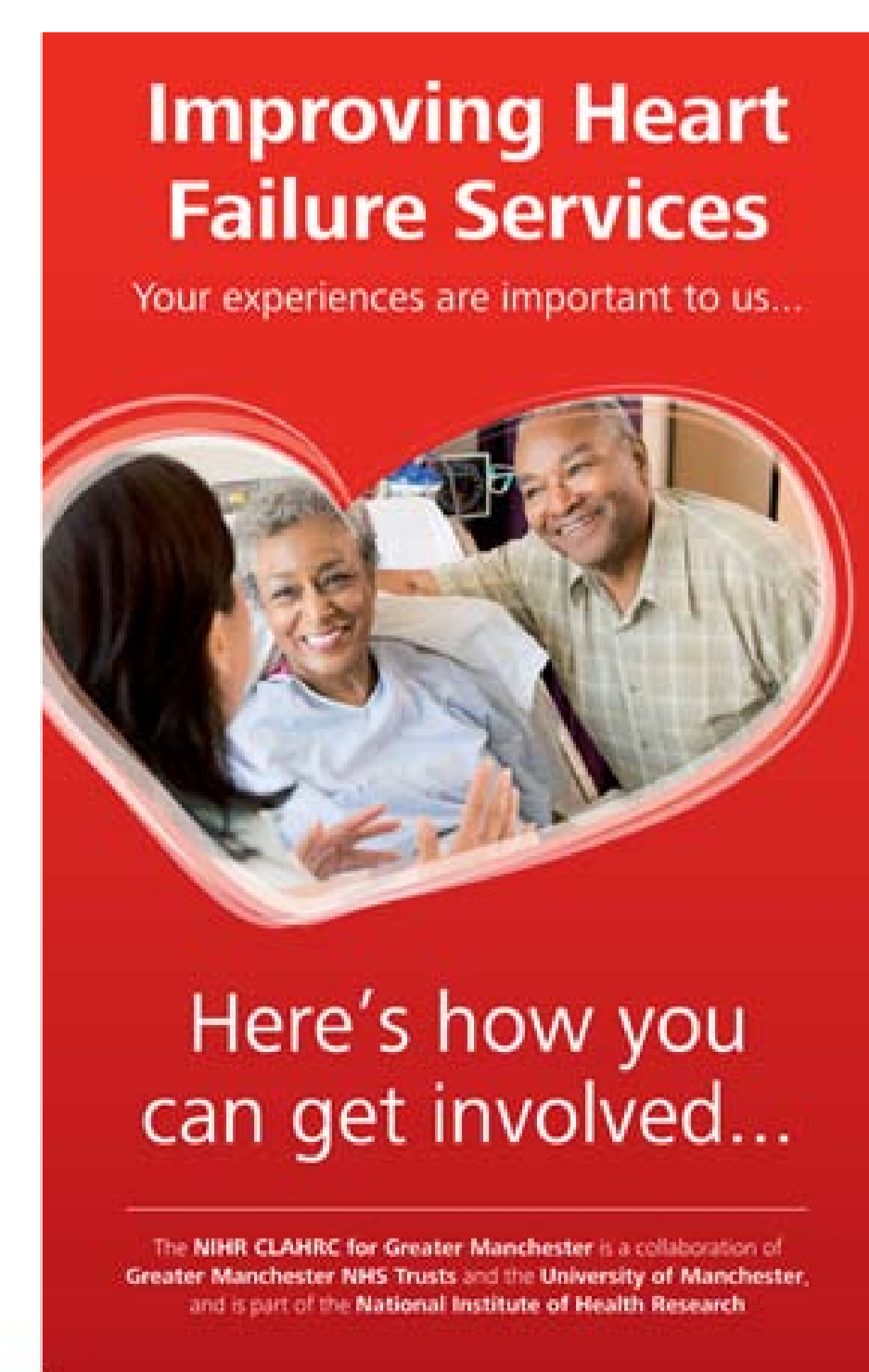
- (1) What information and communication needs are limiting healthcare professionals in their work to provide co-ordinated, multi-professional care to heart failure patients?
- (2) What do patients and carers need to manage their conditions?
- (3) What resources exist to address those needs and what gaps remain?
- (4) What is the evidence for providing this information through a website?

## Methods:

### Initial User involvement:

Opinion and consensus was gained via two initial multi-professional stakeholder meetings and around **30 interviews with healthcare professionals** involved with the care of HF patients across primary, community and secondary care. Figure 1 highlights the key themes deduced from this extensive scoping process. In terms of 'communication', it was clear that health care professionals desired a central information base.

Three focus groups, attended by **15 patients and carers** were held across Manchester to gather input into the design, language, navigation and content of the website. There was a lot of discussion around the use of websites for health information, their credibility and ease of use. Interestingly there was a strong preference for the website to be disease specific, rather than generalist i.e. heart failure rather than general cardiac diseases.



"I would like to see some information about medication on the website, because we all take pills and I am never sure what they are actually supposed to be doing. Perhaps if I understood a little bit more it would make me more fastidious in taking them." – workshop 3

Patient and carer workshop feedback

"The Map of Manchester is clear and easy to understand and it's a good way of linking people to the right services for their location." – workshop 2

### Evidence and Design:

Using the internet for health information is increasing at a rapid rate, with research claiming that as many as 80% of internet users visit health websites and over 50% of these users believed that their behaviour was influenced by such health information<sup>2</sup>. In one study it was found that 87% of respondents used the internet for information about a health topic, compared to 71% who obtain information from a health professional<sup>3</sup>. HF is primarily a disease of the elderly and it was initially thought that this may cause a problem with website use. However, in 2009 the **Office for National Statistics (ONS)** identified that the number of over 65s who access the internet has increased by 15% (proportionally) to around 35%.

The GM CLAHRC Manchester Heart Failure website has taken the elderly age of patients into account in its design, utilising advice from **NHS Senior Health** about the use of larger text fonts, contrast adjustments and multi-media options. After consultation with heart failure professionals, patients and carers, it became evident that many patients accessed the internet with the help of a carer or family member.

A trawl of current HF internet resources identified a lack of local information for patients and carers. National and international HF specific websites existed, but patients and carers didn't know what information to 'trust'. Hence the GM CLAHRC Manchester Heart Failure website was designed to endorse and link to the excellent information which already existed on the web, from:

- (a) **ESC Heart Failure Matters** <http://www.heartfailurematters.org>
- (b) **British Heart Foundation** <http://www.bhf.org.uk>
- (c) **The American Heart Association** <http://www.heart.org>
- (d) **Health Talk Online** <http://www.healthtalkonline.org>

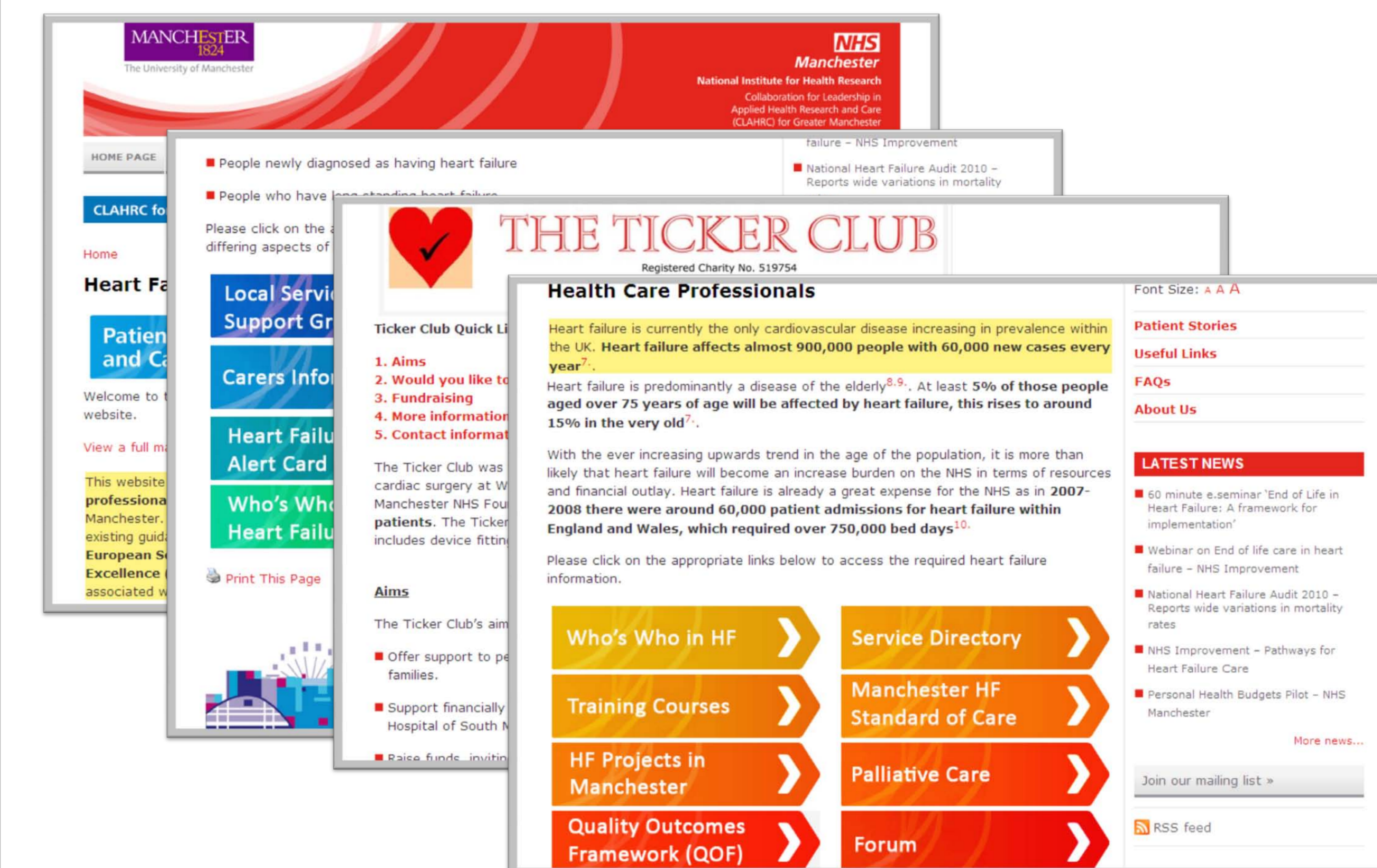


This was supplemented by local service information for patients, carers and health care professionals. This was developed by linking to the appropriate primary & community care services provided by **NHS Manchester** and liaising with local patient and carer associations:

- (a) **The Ticker Club**
- (b) **Withington Heart Help Support Group** (picture on the left)
- (c) **North Manchester Heart Beat Club**
- (d) **Manchester Carers Forum**
- (e) **Manchester Carers Centre**

The clinical aspect of the website was developed through discussions with local heart failure specialist clinicians and the project's clinical lead **Prof. Christi Deaton**.

## Results:



<http://clahrc-gm.nihr.ac.uk/heartfailure>

The website is a 'one stop shop' for HF patients, carers and clinicians; providing specific information about diagnosis, medication, self management, service information and biographies of local clinicians. The website has generated interest and collaborative working with new HF related organisations. Specifically with a local HF charity around the design of a patient 'Heart Failure Traffic Light' information guide :

- (a) **Pumping Marvellous** <http://pumpingmarvellous.com>



It has also provided a great resource for local patient and carer groups to promote themselves to GPs, secondary care health care professionals and patients.

The website went live in September 2010 with a soft launch, with further development and evaluation scheduled for 2012. The continuous development has been hampered due to the rapidly changing primary care context and the ongoing restructuring of the National Health Service.

## Conclusions:

It is possible to design an internationally grounded, locally-focused, disease specific website which is attractive and accessible to health care professionals, patients and carers. It requires the commitment and expertise of a product manager; clinical and technical experts; patients and carers, and a process for achieving a sensitive balance between comprehensive coverage and, accessibility and appropriateness.

However, for the continuous development, updating and management, there needs to be an associated organisation (host) who will undertake such actions, along with a targeted marketing and communications strategy. Currently in Manchester (largely due to the political context) this has not happened.