In Attendance:

Elaine Owen (EO) – Chair, Service Improvement Lead for Acute and Specialist Services, Palliative and End of Life Care, Cheshire and Merseyside Clinical Networks

Clare Littlewood, Macmillan Consultant, Palliative Care Medicine, St H and K Teaching NHS Trust,

Archie Rao (AR), Consultant Cardiologist, LHCH

Julie Gaskill (JG), Palliative Care Nurse, Heart Failure Team, Bridgewater Community HC – St Helens

Paul Barry (PB), GP, Knowsley PCT

Amanda Maynard (AM), Heart Failure and Device Nurse Specialist, LHCH

Clare Coppin, Heart Failure Nurse, Bridgewater Community Healthcare, Halton

Vikki Ludgate, Heart Failure Nurse, Arrow Park

Karen Dickman (KD), Heart Failure Nurse, Knowsley CVD

Amanda Worthington (AW), Heart Failure Nurse, Knowsley CVD

Anne Porter (AP), Service Improvement Manager, Cardiac, CMCN

Apologies received from:

Clare Brewer (CB), Community Matron, 5 Boroughs Partnership, CHS

Jeff Goldstone, (JG),

Marj Carey (MC), Heart Failure Nurse, Knowsley CVD Team Leader

Sarah Ellison, Heart Failure Specialist Nurse, Cheshire and Wirral Partnership, NHS Trust

Diane Barker, Consultant Cardiologist, Arrowe Park Hospital

Ken Blasbery Patient Representative
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<tr>
<th>Agenda Item</th>
<th>Notes/Action points</th>
<th>Lead</th>
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<td>1.</td>
<td>EO welcomed new members to the group.</td>
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<td>2.</td>
<td>Action Notes of the previous meeting held on 24th January 2013 were approved.</td>
<td>All</td>
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<td>3.</td>
<td>Matters arising</td>
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<td>a) It was agreed unanimously that EO would continue to chair the Task and Finish Group for Prognostic Indicators.</td>
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<td>b) The Terms of Reference (T o R): The amended T o R, which included recommended changes by CL, were circulated and discussed and finally agreed – highlighting the “Outcomes” – It would be impossible for this group to do anything other than make appropriate recommendations – would not be able to ensure that monitoring took place AP to circulate the final T o R.</td>
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<td>c) Paper for the CAB: Unfortunately the CAB Meeting was cancelled, but the Briefing Paper was given to Wendy O’Connor, Cardiac Programme Lead (CMCN). AP will have an opportunity to mention the Prognostic Indicators Task and Finish Group at the Cardiac Board Meeting on 7th March 2013</td>
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<td>d) Membership: Since the previous meeting the following members have agreed to participate with this group :- Ken Blasbery- Patient Representative; Jeff Goldstone, GP; Archie Rao, Consultant Cardiologist LHCH</td>
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<td>e) EO explained about Standards for E o L Care.</td>
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<td>Unfortunately Prognostic Indicators does not fit into these. Consideration needs to be given as to how this information can be added/accessed from individual practitioners IT systems; there will be a cost; could be a recommendation for this group</td>
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<td>4.</td>
<td>Use of/ Experience of Prognostic Indicators from members of the group. General discussion took place about the following Tools:-</td>
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<td>a) <strong>Knowsley Trigger Tool</strong> – currently only in a draft format, but was designed to quantify what “Gut Feeling” meant, then as a form of communication to have with the GP, to raise their awareness of the GSF and appropriate treatment at the end of their lives</td>
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<td>b) <strong>SEATTLE</strong> <a href="http://depts.washington.edu/shfm/">http://depts.washington.edu/shfm/</a> -Low sensitivity will miss patients if trigger point is median survival of less than one year</td>
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c) MAGGIC (Meta-Analysis Global Group in Chronic heart failure)  
www.heartfailurerisk.org – currently being used by LHCH, RLBUHT (Jason Pyatt); Arrowe Park, (Diane Barker) and Knowsley CVD (Joe Mills). 
Snapshot at present as has only been used for relatively small numbers and the findings are ongoing- some patients would not have been picked up, prior to using this tool; high correlation between this and the GSF; 
MAGGIC is Cardiac Specific and easy to use 

d) GSF alone  
PB just uses the GSF and is quite confident to identify patients at the End of their lives, without being directed by a Consultant Cardiologist. 
However, this is not common practice, because GP’s without a special interest in Cardiology, can be quite overwhelmed by this complicated patient group 

It was emphasized that the attitudes and knowledge of those on the group were not representative of members of the MDT across the Network

- Some GP’s have little knowledge about End of Life processes. 
- Some clinicians and patients do not like the GSF 
- Some Consultant Cardiologists are reluctant to direct patients to the GSF 
- Some GP’s are reluctant to signpost to the GSF, without direction from the Cardiologist 
- Not everybody understands the process of Advance Care Planning, utilizing the Preferred Priorities for Care 
- Some HF Specialist Nurses do not feel adequately empowered to influence the GP’s or Cardiologist

5. Way forward and objectives by next meeting

a) AP to circulate the link to the MAGGIC Tool asap
b) Knowsley to continue using their Trigger Tool – will provide more info and continue to filter info through to the GP’s. If they are using this tool, to facilitate registering the patient onto the GSF, it is vital that the patient knows what is happening and those difficult conversations take place 
c) EO and AP to draft some recommendations, as a result of the meeting, then circulate to the group and representatives of the rest of the Network, requesting feedback, prior to the final meeting from the following points:

- Whatever is produced will need to be user friendly for the GP’s 
- Anticipate that this could potentially be a local enhanced service for the GP’s 
- Needs to be accessed electronically and appropriate costs identified 
- Needs to be driven from Network Level and validated /endorsed by a
Consultant Cardiologist

- Initial document/form needs to be completed/commenced in secondary care, preferably by the HFSN.
- Has to be sustainable
- Ideal if it was a Commission Lead Service
- Would have to be supported by an educational roll out plan to all members of the MDT – funds need to be identified - ? from CCG’s
- This work would link in very nicely with the “Deaths from cardiovascular diseases – Implications for end of life care in England” National End of Life Care Programme - [http://www.endoflifecare-intelligence.org.uk/resources/publications/deaths_from_cardiovascular_diseases.aspx](http://www.endoflifecare-intelligence.org.uk/resources/publications/deaths_from_cardiovascular_diseases.aspx), where it highlights that responsibility lies with the Primary Care Teams
- Can only work by “drip feeding approach”
- Could be a staged approach
- Could be linked with a CQIN for End of Life -% patients on the Liverpool Care Pathway; % seen by the specialist Palliative Care Team with documented Preferred Priorities for Care etc
- Amber Care Bundle is a Tool used to identify patients in the last 1-2 months of life and would prove to be useful to use in Cardiology. It is currently being piloted in some areas across the Network [http://www.ambercarebundle.org/Resources/Resources.aspx](http://www.ambercarebundle.org/Resources/Resources.aspx)

6. **Draft Recommendations to Cardiac Network Board (to be discussed at meeting on the 21st March 2013)**

1. The following tools adequately identify patients with heart failure who are in the last year of life:
   - Knowsley Trigger Tool
   - MAGGIC(Meta-Analysis Global Group in Chronic heart Failure)
   - Gold Standards Framework Prognostic Indicators for heart Failure
   It is therefore recommended that heart failure teams across Cheshire and Merseyside should use one of the above the tools as preferred

2. To review the use of these tools after six months; to establish if one proves to be more sensitive to identifying patients in the last year of life; then agree which tool should be used across Cheshire and Merseyside

3. Briefing paper for CCGs, to be written re outcomes and work of the group, after the 3rd meeting in March

4. Members of the current group to consider if they would like to be involved in “Stage 2”
7. Agree a plan to communicate with those unable to attend the next meeting
   (This was not discussed but EO and AP have agreed to identify and contact these people)

Date & Time of next meeting: Thursday 21st March 2013- 2 til 4, Willowbrook Hospice,
Portico Lane, Prescot, Merseyside, L34 2QT