

## Adult Care Information Network

### Managing long-term conditions across health and social care – including the positive contribution of information

11 February 2009, Edinburgh

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#### 1. HEADLINE POINTS : what we **discussed, learnt, and concluded:**

- The different countries face **similar challenges** and dilemmas, such as data sharing and confidentiality with potential for common solutions - to hold person-level data, “pseudonymisation” with encryption may be a solution
- To support data **sharing** more effort is needed on developing **data standards**
- There will be **growth** in LTCs and end of life conditions and a need for lots of support for individuals – this will affect both Health & Social Care
- We need to use the **available models** and tools for a more systematic approach to planning and targeting social care, which both improves quality of life for individuals and reduces unplanned admissions through enabling earlier interventions
- **Predictive** tools do work and can join up health and social care data
- For people with LTCs in the high risk categories, there is only a **partial match** between those known through health and through social care records
- Adopting a patient-centred perspective identifies different benefits from a focus on the organisational viewpoint
- We need to “**shift the culture** from cure to care”
- Embedding LTC improvement in **partnership** systems is needed
- There are political as well as systems **barriers** to change
- It was proposed that a UK wide ACIN event on **Risk Prediction** be held.

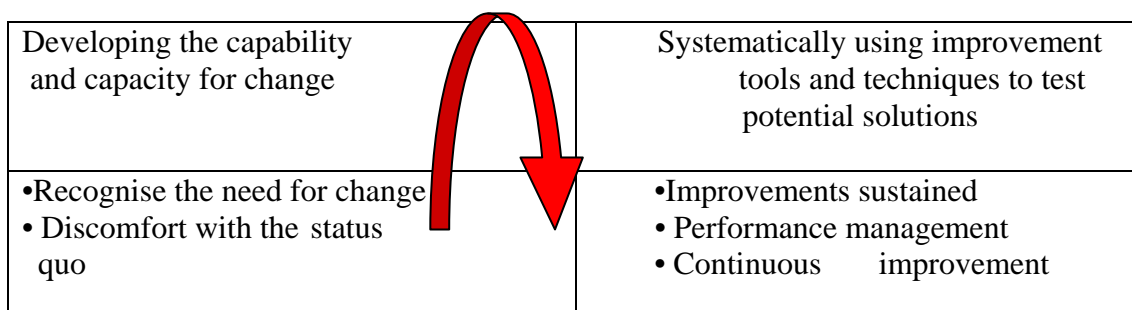
**A range of models and good practice initiatives** were presented, which are using information to drive improvement in LTCs. Digital stories featuring patient experiences of LTCs and complex needs, were also shared. The programmes presented comprised:

- LTC Collaborative in Scotland (Dr Anne Hendry)
- Progress with SPARRA - a risk prediction tool (Peter Martin)
- Partnerships: using information to support improvement (Margaret-Anne Dale)
- Integrated Care Management (Janette Barrie)
- Preventing admission to care homes through upstream interventions (Martin Bardsley)
- How use of Telehealth and Telecase in managing LTCs can present hospital admissions (Sue Williams and Matt Pye).

## **2. MAIN THEMES AND POINTS FROM THE PRESENTATIONS** were:

### **The LTC Collaborative project in Scotland – Dr Anne Hendry**

- The focus has been too much on providing a “fire and rescue service downstream” and on complex Health & Social Care (H&SC), with insufficient emphasis on the “upstream”.
- Change needs to address systems and cultural issues, and hence the Collaborative have developed a collaborative model of change and improvement.
- This is using information to drive care improvement, with the emphasis on data sharing between partners.



- The process aims to drive change systematically across the system. It has developed work-streams with programmes of action at different levels of intensity of need and intervention, to deliver system transformation

### **LTC Collaborative process**

Whole system transformation

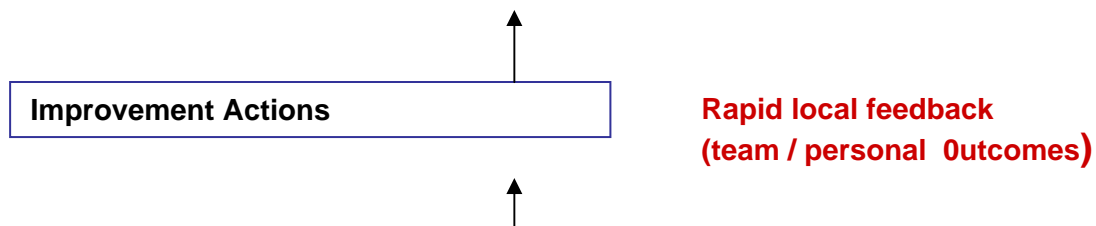
LTC Collaborative



### **Measures**

**HEAT / SOA**  
(system outcomes)

**Local and national**  
**Measures for improvement**



### Series of PDSA (Plan –do-Study-Act) cycles

The Collaborative’s logic model for delivering outcomes in social care is at Appendix 2.

#### **Progress with SPARRA - a risk prediction tool - Peter Martin**

- SPARRA is a predictive tool used to generate risk scores at both patient and aggregated levels for localities – but how good is its predictive power?
- It has been further developed recently and the new model identifies twice as many patients as high risk, with new client groups eg those at risk due to substance misuse.
- Is currently being enhanced to use “case funding” – putting people at risk “on our radar”. Widening focus beyond past admissions: using prediction to look further ahead ie more than 1 year ahead: identifying those likely to become at high risk.
- We need a definition of “case care management” as there are so many different models (eg further assessment, anticipatory care, self management plans, dedicated case management). SPARRA is aiming to establish from the range of case finding / risk stratification tools in operation or being developed, which tools work in a social care setting, and “what is best practice and make sure everyone is using it”.
- It is expected to mean:
  - more assessment
  - multi-disciplinary assessment
  - referral
  - anticipatory care plans.

#### **Partnerships: using information to support improvement - Margaret-Anne Dale**

- The evaluation report on project was being prepared for launch on 4 March 2009, until which the details from this preview remained confidential until then
- Broadly, the project has demonstrated the value of bringing information together and including social care data.
- The project’s aim was to use local H&SC data to inform practice in case management and anticipatory care.
- The focus was a SW Glasgow population of 5000 patients in a relatively deprived area
- The key finding was the relatively limited match between patients at risk identified by the health and the social care systems, they found that only about 50% of the at risk “health” patients marched to open social work cases.

- Revealed challenges: around patient consent/confidentiality
- Revealed lots of data quality issues eg what info is NOT being recorded (eg living arrangements, H/h composition, and raised the question of what other data should be included eg GP data, disease register, falls.

### **Integrated Care Management in Lanarkshire - Use of SPARRA in the front line: Janette Barrie**

- An integrated model of care management, using a proactive approach and co-ordinated that focuses on high risk patients with LTCs who have a combination of physical and social needs
- Approach included motivational interviewing and coaching of Service Users and carers.
- Brought together SPARRA and the **LIVE** tool (Lanarkshire Identification of Vulnerable Elderly), along with clinical judgement
- Timely access to information on services has enabled earlier interventions
- This programme has made a difference: of the patients accepted onto the, LoS fell; and feedback on quality of care and patient satisfaction improved
- 
- Benefits gained included better outcomes for individuals and their carers and families, improved choice and empowerment, speedier decision-making, fewer professionals involved with an individual and reduced use of unplanned care.
- Must “shift the focus from the myth of cure to the reality of care”
- The Model used for identifying patients is attached at Appendix 3.

### **Predicting social care costs and preventing admission to social care homes through upstream interventions - Martin Bardsley, Nuffield Trust**

- Outlines feasibility study (funded by DH) for development of statistically valid models that would identify people at risk of incurring significant social care costs.
- Is equivalent to work on PARR and combined model.
- Designed to use existing data records – from both health AND social care, rather than be based on interview assessment.
- The advantage of this would be that predictions would be based on “routine” data, and be less labour intensive, so that the population could be stratified systematically and repeatedly.
- The model would seek to identify people earlier, with lower but emerging risks.
- It would seek to identify what are the key factors predictive of a future admission to social care home and what interventions might be most effective in delaying admission.
- It would seek to find out whether such a model can be used in front line settings, and the main barriers to routine implementation.
- The model for seeking patterns in routine data is attached as Appendix 4. The purpose of the predictive model is attached as Appendix 5.

His key observations at the “halfway” stage of development are that:

- The project is ambitious

- Generally the data do exist in local systems and most are accessible at person/user level (some exceptions eg older community systems)
- There is a lack of data in some essential areas such as information on Older People, community information, social networks, or it is not recorded consistently.
- Some significant strategic changes will be needed to make this model workable in practice

### **Kent TeleHealth Evaluative Pilot - Sue Williams and Matt Pye, Kent County Council**

- This scheme is a Whole Systems Demonstrator site and aims to focus “lower down” than the apex of the triangle.
- Their model of Care Management is included at Appendix 6.
- Telehealth and Telecare aim to help self-management of long term conditions and prevent admissions to hospitals. Its potential is for use in targeted reduction rather than prevention of service use.
- Case studies exemplify the benefits of moving from a re-active and service-centred approach towards pro-active care and a patient-centred approach including:
  - Early interventions
  - Fewer exacerbations
  - Improved quality of life
  - Reduced anxiety/increased confidence
  - Increased independence for service users & informal carer(s)
- As well as:
  - Delayed placement into care setting
  - Reduction in ad hoc acute care and care packages
- Adopting a patient-centred perspective identifies different benefits from a focus on the organisational viewpoint
  - Improved medicines management
- Adopting a patient-centred perspective identifies different benefits from a focus on the organisational viewpoint

### **Key challenges and issues overall** were seen to be:

- Demand for support for LTCs will increase and this presents a major challenge for the future
- There are many different LTCs but they share common problems and we can share common solutions
- How we make measurement for improvement smart?
- How to create an enabling information infrastructure?
- Setting up an integrated system needs investment in the supporting infrastructure and protocols and pathways – communication is key
- Embedding LTC improvement in partnership systems
- Keeping real LTC patients “on our radar”
- People at risk often have multiple (say 4/5) LTCs and are often in a care cycle eg have already experienced hosp admission
- Not all admissions are preventable by earlier interventions!

- We need to look back at the difference that has been made to a person's life by early identification of being at risk!
- Must “shift the focus from the myth of cure to the reality of care” (Janette Barrie)
- Essential to align national policy and local strategy.

### **3. MAIN POINTS FROM WORKSHOP DISCUSSIONS**

The participants held two workshops, discussing the questions of:

- **Should LTCs be better integrated with the health and social care agenda?**
- **Is there enough data on LTCs? What is missing?**

**Main points** from the debate were:

- There are good examples of **models** of care but we need to use them on a wider scale. Combined **PARR** using GP data is an important development. UDSET is seen as having an important place in LTCs management: developed through combined working of Health & Social Care, which showed the value of good information and good quality data
- There are tensions between **local and national** approaches - between allowing local solutions to joining up eg SW Glasgow which used surnames as the common data identifier as opposed to nationally determined systems and standards
- The question should be – should H&SC and information be better integrated to support LTCs? The need and aim is connecting people, giving people info and intelligence to make sensible **decisions**. Data is under-utilised – slowly created and slowly fed through to “the frontline” – we need to make more information available
- How should we **define** LTCs? Can be seen as upper part of the condition triangle ie defined by intensity of experience of the Long term condition rather than as a risk factor. In a condition-cycle it is the later part ie excludes the preventative agenda.
- There will be **growth** in LTCs and end of life conditions and need for lots of support for individuals – this will affect both Health & Social Care
- LTC in Scotland is focussing on LTCs as joint responsibility of H&SC – imperative that H&SC policy and activity reinforce the need to collaborate now LTC management needs to be owned by Health AND Social Care
- Effective care for older people requires data **sharing** and therefore **data standards** for this. Whilst Scotland has National Minimum Information Standards for assessment, care planning, review and carers assessment,
- There are no Data **Standards** on Social Care in England. There is a need for clarity around what data you can and can't share. We need speedier

development of data standards to ensure consistency of language, data and information systems. Data **sharing** across H&SC is an issue that has not been solved. Can the Scottish Government help more to set standards and integrate IT systems? Is there a public health duty to allow data sharing for better care?

- **Confidentiality** issues that block sharing of GP data must be solved eg work towards anonymisation of GP data extraction, so as to improve the care of individuals
- Users/Patients want us to share information for their benefit. The cared for person assumes data is being shared and becomes frustrated at the **duplication**: the carer becomes the coordinator.
- There are challenges in keeping **datasets up to date** – some links are manual
- Much of the social care info in England is **aggregate** data while in Scotland there is lots of individual data but it is not joined up.
- Implications of new **shared assessment frameworks** – CAA, single outcomes agreement: social care does not have key position? In health you get measured on “what makes a difference” eg statins – no equivalent for social care. Gap is on quality assessment
- Health is better than social care on consistency of recording . There are barriers to admitting that the **data** is poor & barriers to admitting that the **data collection** is poor
- Need for **improvement** in joining up community care data, especially as this is the direction in which care is supposed to be going
- The possibility of pseudonymisation was discussed, but the implications of this were unclear in relation to patient confidentiality.
- Possible actions – change **drivers** eg who GPs see – could be more proactive; capture missing data – soft data eg social networks; carers (some in CADS)
- There are political as well as systems **barriers** to change
- How can we do better? We need to “**sell**” **the benefits** of information sharing to a greater extent – sharing information and working together can make a difference to LTCs. Need to make it clear to the public that their data is safe and that there are many advantages in us sharing their information.
- It was proposed that a UK wide event on **Risk Prediction** be held

#### **4. SUMMARY**

Similarities were noted between the challenges faced by the different countries, and the approaches used eg predictive tools. Challenges include data sharing and

confidentiality and it was noted that Nuffield use “pseudonymisation” with encryption to hold person-level data.

There is much opportunity to join up information, both between health and social care and within health and within social care..

Anne Hendry: Need for more attention to upstream as opposed to “fire and rescue service downstream”; need to do it systematically across the system”.

Peter Martin: The SPARRA predictive tool is currently being enhanced to use “case funding” – putting people at risk “on our radar” - using prediction to look further ahead and identifying those likely to become at high risk.

Margaret-Ann Dale: Case finding has identified that many patients identified as at risk through health records do not match with open social care cases. Data quality issues eg we do not record living conditions

Janette Barrie: Predictive tools and modelling aim to identify those at risk and reduce unplanned access to care/plan earlier interventions. We need to “shift the culture from cure to care”.

Martin Bardsley: It appears feasible to develop a statistically valid model to predict social care risk and using collected rather than interview data. However, There is a lack of data in some essential areas such as information on Older People, community information, social networks, or it is not recorded consistently.

Sue Williams and Matt Pye: Telehealth and Telecare aim to help self-management of long term conditions and prevent admissions to hospitals. Moving towards pro-active care and a patient-centred approach benefits both patients and care providers.

#### Workshops:

- There are good examples of models of care but we need to use them on a wider scale.
- There are tensions between **local and national** approaches - between allowing local solutions to joining up eg SW Glasgow which used surnames as the common data identifier as opposed to nationally determined systems and standards
- Data is **under-utilised** – we need to make more information available
- We are hampered by a **lack of consistency** eg in information systems
- We need to demonstrate what makes a **difference in interventions**
- Things take **time** – to set up pilot projects, obtain permissions, generate outcomes
- Communications and **relationships** are key
- To support data **sharing** more effort is needed on developing **data standards**
- There are implications arising from new **shared assessment frameworks**
- We need to “**sell**” the **benefits** of information sharing to a greater extent – sharing information and working together can make a difference to LTCs. Need to make it clear to the public that their data is safe and that there are many advantages in us sharing their information.

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## 5. GLOSSARY:

CADS	Care & Assessment Data Summary
H&SC	Health & Social Care
LIVE	Lanarkshire Identification of Vulnerable Elderly (tool)
LTCs	Long Term Conditions
SOA	Single Outcomes Agreement
SPARRA	Scottish Patients at Risk of Readmission and Admission
UDSET	UDSET The User Defined Service Evaluation Toolkit
WSD	Whole System Demonstrator (programme)

## 6. FURTHER SOURCES:

[www.isdscotland.org/ltc](http://www.isdscotland.org/ltc)

## Appendix 1: Adult Care Information Network

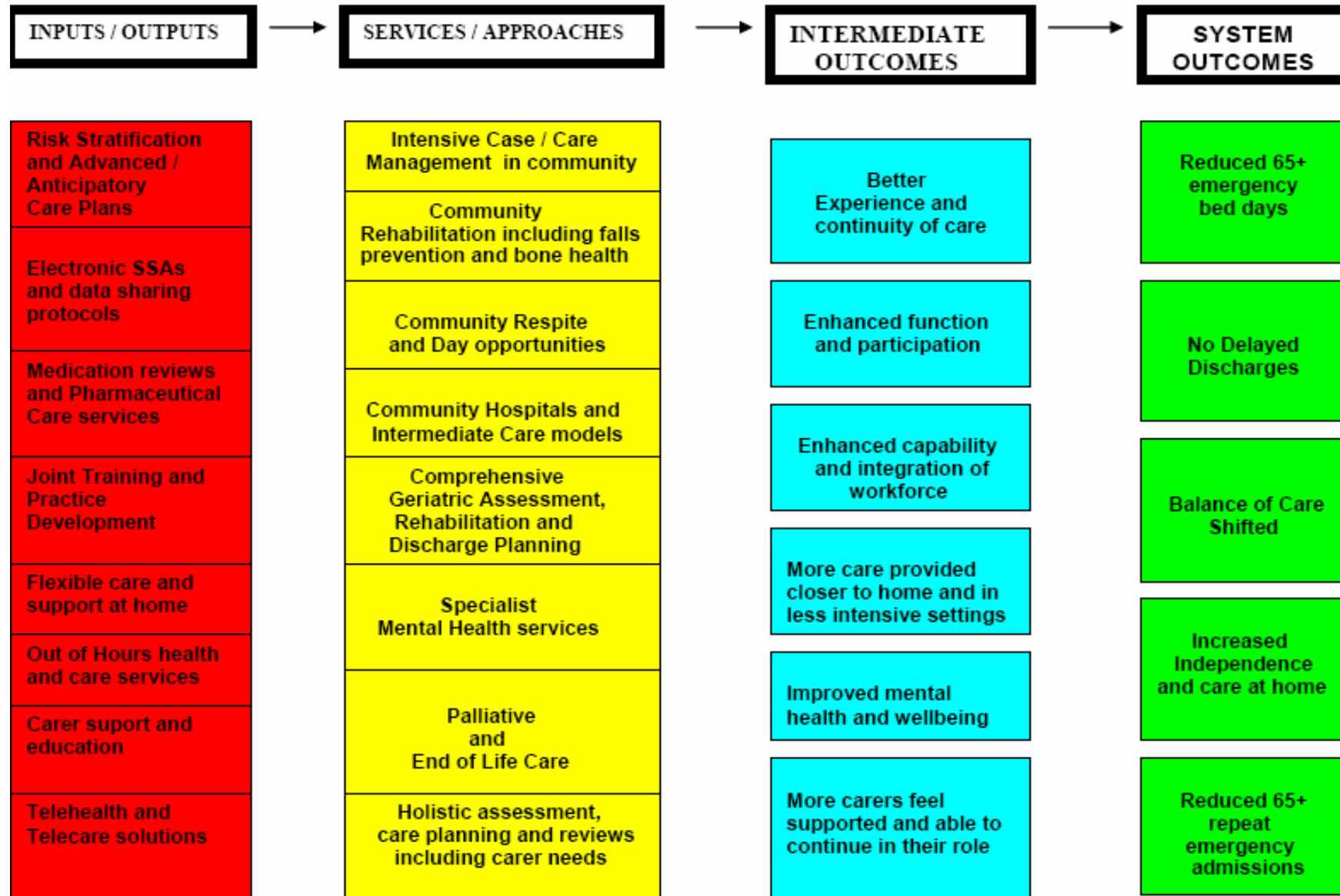
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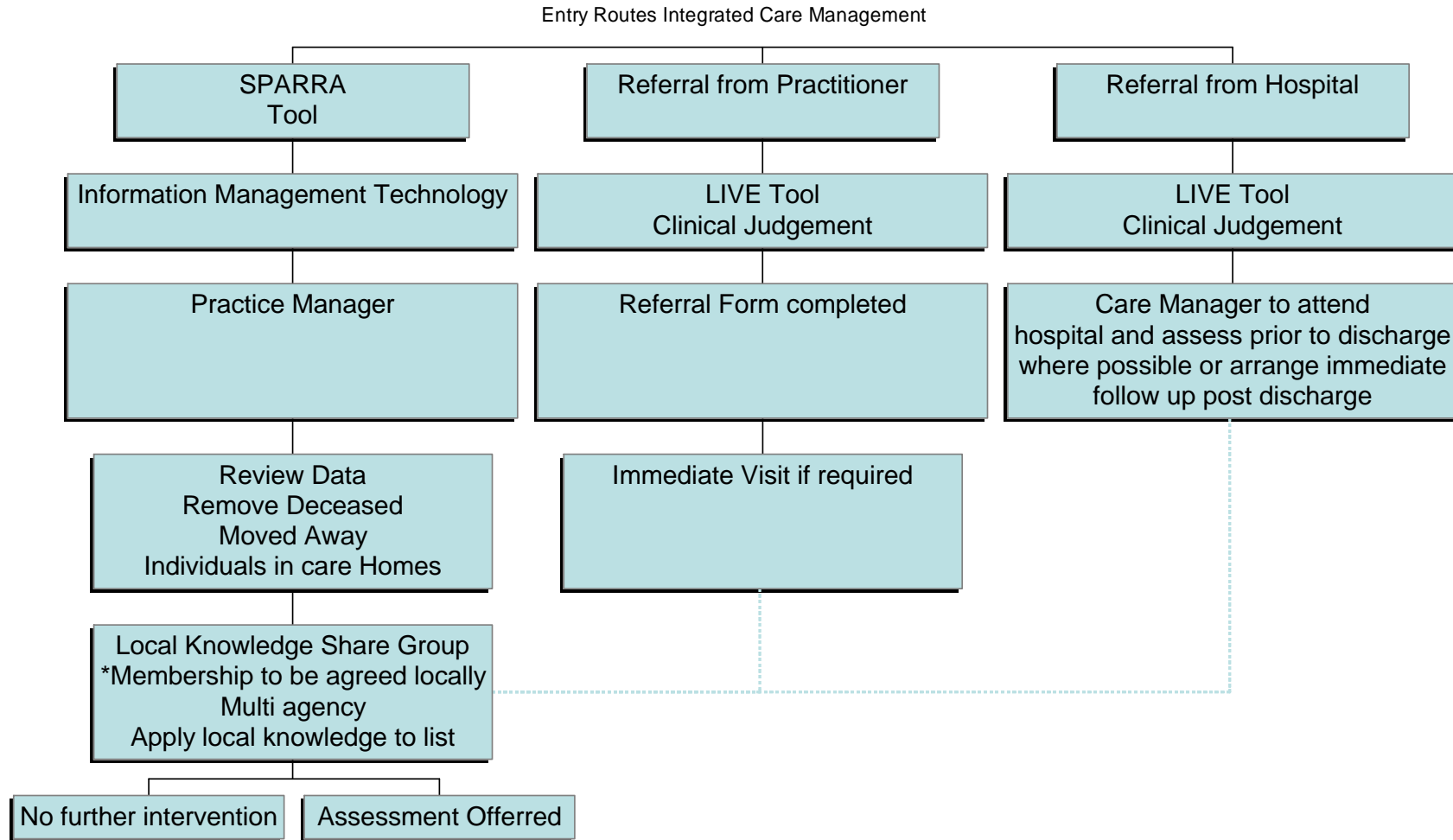
Apex International hotel, Grassmarket, Edinburgh

10.00	Coffee and arrivals
10.30	Introduction – Lorna Jackson, ISD Scotland
1045	Good practice and initiatives in Scotland - DrAnne Hendry, Consultant Geriatrician & National Clinical Lead, Long Term Conditions Collaborative
	Digital story: a patient with complex LTC needs
1050	Outline of the Long Term Conditions Collaborative
1105	Progress with SPARRA a risk prediction tool, Peter Martin, ISD Scotland
1120	Partnerships: using information to support improvement, Margaret-Anne Dale; & Integrated Care Management, Janette Barrie
1140	Digital Story: staff working on LTCs
1145	Q&A
<b>1200</b>	<b>Coffee</b>
1215	Workshop: Should long-term conditions be better integrated with the health and social care agenda?
<b>1315</b>	<b>Lunch</b>
1400	Preventing admission to care homes through upstream interventions – Martin Bardsley, Nuffield Trust
1440	How use of Telehealth and Telecase in managing LTCs can present hospital admissions (Sue Williams and Matt Pye, Kent CC).
1515	Discussion
<b>1530</b>	<b>Coffee</b>
1550	Workshop: Is there enough relevant information on LTCs – what's missing?
1620	Summing up
1640-1700	Close with Optional evening dinner

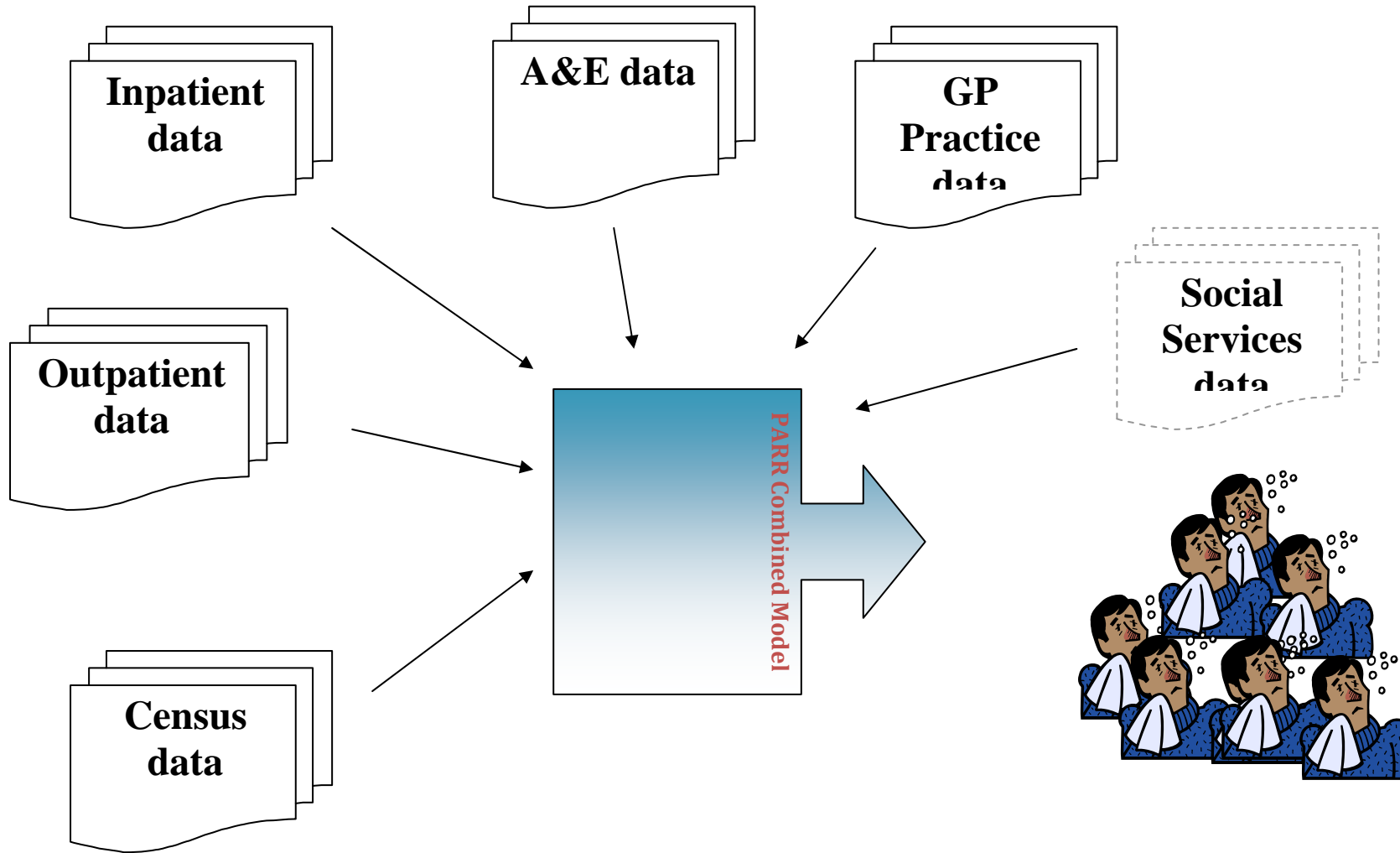
Appendix 2 Logic model – Dr Anne Hendry



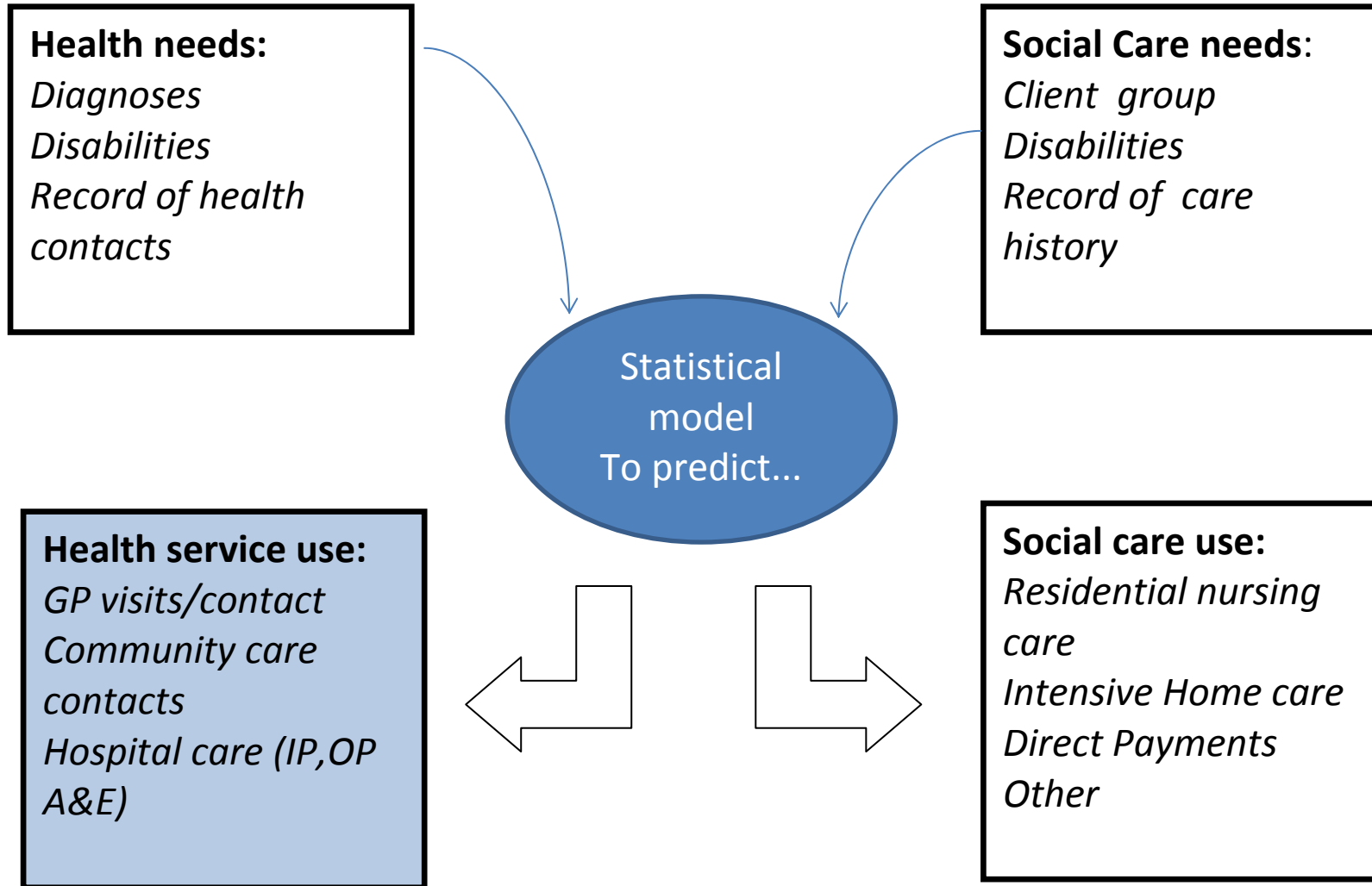
**Appendix 3 Model for Integrated Care Management in Lanarkshire and use of information – Janette Barrie**



Appendix 4 Model for seeking predictive patterns regarding social care home admission from routine data – Martin Bardsley



Appendix 5 Purpose of the predictive model of social care costs – Martin Bardsley



Appendix 6 Combined Model of Kent CC care Management and Scotland's LTC Collaborative model

**Targeting  
Population(s)**

**Redesigning  
Processes**

**Measurement of  
Outcomes & Feedback**

