Modest and mighty: stories of health and well being from Langside and Linn

Final report
Langside and Linn Health Forum

"It is easy to forget how mysterious and mighty stories are." (Ben Okri)

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Acknowledgements and thanks

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Introduction

In March 2009 Langside and Linn Health Forum commissioned us to undertake research, which aimed to develop an in-depth understanding of the health experience of local people. The Forum was keen to use a 'coproduction' approach which really engaged both local people and local professionals. In the event they proved to be very willing to be involved both as story gatherers and story tellers and were open about the issues that concerned them.

The results of the research were both compelling and provocative. Story gatherers were often profoundly moved by the stories they heard. Stories revealed telling messages about the attitudes encountered by local people using services, the lack of joined up practice and the hurdles they faced when trying to access basic information. Many of the issues identified required communities and services to work together to address systemic problems, which defied traditional service solutions. Although money was mentioned, lack of funding was only one of several fundamental issues.

The research serves as a modest illustration of how the 'inverse care law' actually operates; the inverse care law states that *'the availability of good medical care tends to vary inversely with the need for it in the population served'*[1]. Whilst this research was not designed to be an investigation of primary care, many of the substantive findings do illustrate the 'human narrative' and the dynamics of inter-personal effectiveness in encounters between people living in deprived areas and health care professionals, including, but not exclusively, their GPs.

The recommendations reflect a conviction that the process used has much to offer as a way of really hearing the voice of communities. They identify approaches and solutions, for community and voluntary groups working in the area as well as professionals and health improvement services at every level.

The Process

In total 43 stories were collected around 16 themes or 'stretching statements' by 16 story gatherers. These stories were analysed, and used as the basis for recommendations by members of the health forum who formed an action research 'Hub'.

The value of using an action research methodology based on story gathering by local people and local professionals was continually remarked upon by Hub members and

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[1] *Stewart W. Mercer and Graham C. M. Watt, The Inverse Care Law: Clinical Primary Care Encounters in Deprived and Affluent Areas of Scotland,* Annals of Family Medicine, Vol. 5, No. 6 November/ December 2007

story collectors. This has modelled a process, which has the potential to become a 'way of working' within the Health Forum and with partner agencies.

The process has challenged the assumption that the problems of change at the local level are primarily about a deficiency of evidence, deficit within the community or unwillingness of people to share their stories or get involved – this process shows that they do care and will share if asked in the right way.

The limited 'reach' of the research (using service providers & local community members) also mirrors the reach of the services - this seems to be a lesson for services too. This suggests a challenge for services to be more 'culturally competent' in recognising how they engage with people, the questions they ask and the information they give. A more regular process of seeking and giving feedback through some kind of collective 'story-based' process could enhance the development of this competency amongst individuals and strengthen the role and impact of the Health Forum.

Conclusions and Recommendations

The process of analysing and reflecting on the themes generated by the stories led 'Hub' members to make a series of recommendations, which are outlined below.

As facilitators, our main recommendation to the Health Forum is that this process should continue as an embedded part of how the Forum operates[2]. This could enable the Forum to identify the health issues that really matter to local people, and continue reflecting on the best ways to tackle these.

Adopt action research as a way of working
Our recommendation is that this approach should become a 'way of working' for the Hub echoes their own enthusiasm that they should continue to share and learn from best practice. Such an approach would give them the structure and tools to explore the successes, problems, contradictions, assumptions and prejudices in the organisations and communities in which they work in order to find new practical ways of acting. It also has the potential to draw in others as it proceeds and to strengthen partnership working.

Building on what's working well
The Forum wanted to see a more 'appreciative' approach to their work in order that good practice is recognised, rewarded and shared. As this research has shown, this is a good starting point for inquiry. This includes the need to be better at on-going self-evaluation and feedback. Their recommendations were
> a) the health forums in the area should get together regularly to share and celebrate good practice.

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[2] This does not need continuing external facilitation.

b) funders, in particular the CHCP should invest in things that are working well over the long term.

c) the Health Forum should develop a baseline for good practice and get better at capturing the difference we make (through the use of story telling among other methods).

d) the Health Forum should ensure that community members get feedback about changes being made as a result of their contributions.

Tackling what's not working well

Much of what was not working well centred on how people found out about and accessed services. Hub members made a series of recommendations aimed at enabling services to improve their practice:

a) all services should improve their marketing and aim it at particular audiences eg. parents

b) services need to strengthen partnership and build on the networks we have – the Health Forum has a role to play in facilitating this.

c) services should make more use of 'well-kent' faces to reach those people in the community defined as 'hard to reach'.

d) the Health Forum should review what we are learning on a regular basis.

Promoting access and confident self-advocacy

Part of the learning from the process is that the way that services are provided sets up barriers that exclude people in ways that are not easy to see, categorise or anticipate. In practice, many people do not self-identify themselves as belonging to a particular category or group. The original brief had a strong concern about all the six 'Fair for All' equalities strands. The stories illustrate many examples of assumptions being made about people that have acted as barriers to communication and ultimately to services.

Hub members discussed how they could let other professionals know about the struggles community members had in putting their views across and accessing services and how they could make services more responsive to individuals to improve inclusivity and access for all groups. This suggests the need for a more explicit leadership role for the Forum. They recommended that the Health Forum should:

a) work with the Medical Director at the CHCP to inform GPs both about community members' experience of the service in Langside and Linn and about the breadth of health and well-being services available in the community.

b) inform other partners about the issues identified through the research, for example, social work and PACT.

c) ensure that the Stress Centre can operate out of the Medical Centre on a more regular basis.

d) continue the work of building relationships between professionals so that information is shared in a meaningful way.

e) investigate whether GPs really are unwilling to refer people to community based services because of short term funding, and if so, what can be done about it.

Tackling systemic issues

One of the advantages of collecting stories from service users in this way is that it gets at the *'experienced reality'*, highlighting issues around partnership working by illustrating how complex, cross-cutting services work in practice. Several of the issues highlighted in the stories including patient transport and experiences of administrative staff in GPs surgeries, pointed to underlying problems in the system which had an unwelcome 'knock on effect'. Hub members struggled with how to tackle these since they seem to be outwith their direct influence. In the first instance they recommended that the Forum should:

a) use structures within the CHCP to ensure that issues such as patient transport are tackled by those responsible for them.
b) use the story gathering process to keep gathering identifying these kinds of issues.
c) encourage services to have systems for gathering feedback eg. boxes in surgeries.
d) examine coping as an issue both for community members and professionals as part of the health and wellbeing strand of the Health Improvement Plan.

Supporting Community Resilience

Hub members recognised that the natural strength of a community like Castlemilk needed to be built upon and nourished, and that issues of dependency on services needed to be challenged. Again it was a challenge to identify ways of doing this. They recommended that services should:

a) recognise, value and build up pride in the community in whatever way possible.
b) explicitly and consciously enable community members to support each other using examples like the Samaritans service.
c) be creative in using other networks such as housing associations to reach people who are disconnected from support services.

Explore the links with co-production

A co-production approach to service design and delivery brings the kind of individual, family and community knowledge highlighted by the stories into the shaping of both resource allocation and of the strategies deployed to deliver health and wellbeing outcomes. Co-production is an on-going process, not an event and relies on the kind of on-going inquiry that is demonstrated here. We recommend that this action research approach is considered by the South East CHCP as a way of moving further towards services which are truly produced with communities and make the most of natural resilience and supports.

1   Introduction and background

1.1   This report is based on recent research by the Langside and Linn Health Forum[3]. The Health Forum is a collective of voluntary sector organisations, statutory organisations and local people with a remit to identify the health needs of the area and develop appropriate responses. Langside and Linn is a Community Planning Partnership area within South East Glasgow, comprising six neighbourhoods: Langside and Battlefield, Carmunnock, Castlemilk, Cathcart and Simshill, Croftfoot and Kings Park & Mount Florida.

1.2   The Forum was aware that there is a large range of information available on the indicators for health and well being in the area, but felt that this wealth of information does not necessarily help them to fully understand the health experience of local people. The approach to this research was based on their beliefs that:

- Local people and organisations do have a good idea of what works well to support health and wellbeing in this area.

- The statistics only tell us a small part of the picture and can easily miss the things that really matter to people.

- We often don't notice the things that *do* work well, at least some of the time.

- We think that if we are prepared to suspend our usual ways of thinking we might learn something that we can use to develop better health and social care services.

1.3   Within this context, the research aimed to develop an in-depth understanding of the health experience of local people by:

(i)   exploring local views about the factors that have most effect on the health and wellbeing of people in Langside and Linn and;

(ii)   exploring the awareness and use of local services that support health and wellbeing.

1.4   In particular, the research focused on developing a better understanding of the factors which would support more positive health futures for everyone living in Langside and Linn, including those from different equalities groups.

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[3] Jo Kennedy and Cathy Sharp were commissioned by the Langside and Health Forum in February 2009, to undertake a qualitative exploration of health and wellbeing in the Langside and Linn area of South East Glasgow CHCP.

Improving knowledge about access to services, barriers to services and gaps in services and the development of appropriate responses to these issues, was an integral part of the process.

2   Our Approach and Methodology

2.1   In approaching this work, we acknowledged and shared the perspective of the Health Forum. There is a wealth of documentation about the health and well-being challenges facing many communities in Scotland, including community profiles and statistical indicators. Whilst these are of value, they are only a part of the picture and do not illuminate the specific perspective of local people who experience these conditions for themselves and in their wider community.

2.2   Policy makers and practitioners are voicing concerns about how difficult it is to effect change in individual behaviours and wider communities. The enduring prevalence of poor health and well-being and the limited impact of efforts and resources intended to support change, is both frustrating and worrying. The current economic climate simply magnifies this gap between our aspirations for change and the ability to make an impact on the ground through practical action.

2.3   We believe there are two principle reasons why change can be stubborn and slow. Firstly, there is often a restricted idea of what counts as evidence, which discounts the real experience of local people. As a result, services are designed around professional understandings of the issues and their views of local 'needs'. They tend to focus on problems rather than working 'appreciatively' by looking at what works for people. Secondly, an action focus is often missing from research; action is assumed to follow on from inquiry. Evidence is produced through a process, which is not embedded in the context and by people who have a limited understanding of environment.[4].

2.4   We had a strong view that this research needed to be different. Traditional approaches to qualitative research run the risk of providing more information about local people's experience and views, which doesn't lead to action *"....the emphasis of qualitative and interpretive approaches to research has been on representation of the World rather than action within it.[5]"*

2.5   We took an action research approach to the work, founded in the perspectives of local people and informed by the perspectives of service

[4] This argument is developed more fully elsewhere – see Sharp, C. (2005) *The Improvement of Public Sector Delivery: Supporting Evidence Based Practice through Action Research,* Scottish Executive. http://www.scotland.gov.uk/Publications/2005/09/2890219/02201

[5] *Handbook of Qualitative Research*, Denizen and Lincoln, Sage, 2000

providers. In this way, we explored the barriers to access and gaps in services in Langside and Linn. Through the Hub insights could be shared and potential solutions discussed, in a way that, through small beginnings, begins the process of embedding change.

The process adopted was restricted by the time and resources available, but did allow for a modest attempt to 'test out' the resonance of the data with local service providers and service users.

2.6   It is important to establish the validity and quality criteria for this research. The goal of action research is not to 'prove' anything, but to explore the problematic, the contradictions, assumptions and prejudices in a social situation in order to find new practical ways of acting. The basis of the validity and quality of an action research approach lies in the ability to articulate previously unheard perspectives:

> "*Sometimes in action research what is most important is how we can help articulate voices that have been silenced. How do we draw people together in conversation when they were not before?*"[6]

2.7   Good quality action research is aware and transparent about the choices available within the process, with their different strengths and limitations, and the conscious decisions made at each stage of the inquiry. For example, this meant that we did not use a predetermined definition of statistical representativeness, such as the 'equalities groups' as a *starting point* for sampling. We were aware of who was in our sample and who was not; and the Hub made deliberate choices and efforts to seek out those that were missing. This, in itself, generated some useful learning about barriers to access for research and services (4.32-4.33 below).

2.7   The testing of the *resonance* of the stories through the Hub was also vital in ensuring the accountability of the data collection and analysis process. This was a form of significance testing which asks questions such as; *Is this believable, does it feel true and authentic? What sense do we make of this? How does is challenge our understandings and assumptions? What does it suggest we might do, or do differently?*

> "*Representativeness cannot be determined on the basis of the statistical support given to a proposition. It lies in the willingness of people to 'open doors' and walk through them, and the willingness of 'participants' to support a line of action because it makes sense of the reality that they experience.*[7]"

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[6] Source: Reason, P ((2006). Journal of Management Inquiry, 15(2), 187-203. Choice and Quality in Action Research Practice, Journal of Management Inquiry

[7] *Systemic Action Research*, Danny Burns, Policy Press, 2007

Starting out appreciatively

2.8   We began in April 2009, by meeting with the Langside and Linn Health Forum to explain our approach in more detail and enlist their support as an 'action research hub'. The role of Hub members was:

   a) to act as or recruit story gatherers,
   b) to listen to the stories, once enough stories had been gathered
   c) to reflect on and analyse what they were hearing and
   d) develop ways of taking the issues forward so that ultimately the health and wellbeing experiences of local people would be improved.

2.9   In May 2009, we held a story gathering workshop to which members of the local community and service providers were invited. This was publicised as widely as possible through local networks. The aims of the workshop were to:

   a) explain the purpose of the research
   b) explain the methodology we were using and practice 'story telling'
   c) share stories of health and wellbeing
   d) generate 'stretching statements' from these stories, which we could use to as a trigger for other stories as the research progressed
   e) recruit story gatherers.

2.10   The event was attended by around 20 participants and through it we recruited 16 story gatherers. Hub members acted as hosts or facilitators enabling people to tell their stories in small groups and to learn from them.

2.11   During the event we generated 16 stretching statements, shown in Figure 1 below. These statements are grounded in the experience of what is possible, based on stories shared amongst those at the event. In this respect, they differ from a traditional 'vision statement'; they are provocative, but also well grounded in real examples to illustrate the 'ideal future' as a concrete possibility. They describe an outcome that if fully implemented, would make a significant difference to the health and wellbeing of local people in Langside and Linn[8].

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[8] This approach is based on 'appreciative inquiry' and uses the positive statements to assist in the story telling process. It is based on an assumption, that something does work, at least some of the time and that we need to know what those things are in order to build on them. Without this approach, the default tendency would be to elicit a barrage of complaints, and nothing positive at all.

Figure 1: What we know is possible in Langside & Linn: stretching statements

1   Agencies involved in making decisions about service delivery are working really well and are really listening to local people.

2   People with mental health issues feel supported and connected in their community.

3   People are not drinking in ways that are harmful to themselves and others now and in the long term.

4   Local people have better health because they have more influence over services and activities.

5   Pupils will know where to get impartial support about their rights as a child in the education system and wider society.

6   People are informed of their rights regarding confidentiality when accessing sexual health provision.

7   People will know where to go for support and guidance when experiencing multiple health and well-being issues.

8   Men are aware and taking responsibility for their own health.

9   Ex-offenders are being supported to build their lives positively in the community.

10   Young people are supported on their own individual health issues which gives them confidence to move forward.

11   People are more confident and feel part of their community.

12   People recover quickly on leaving hospital because they have good support in place.

13   Older people have their health and social services delivered as appropriate to their individual needs.

14   Families feel supported and connected in their community.

15   Older people are socially active and included in the community.

16   We make the best use of informal opportunities to talk about health and to learn what matters to people.

Story round one – collection and analysis

2.12   We prepared a set of materials for each story gatherer which included:
a) the stretching statements on individual cards
b) story collection sheets (see annex 2)
c) contact details for story gatherers

2.13   During the following weeks, story gatherers went out into the community and gathered stories from a range of sources. In mid-June 2009, we met with the story gatherers to review and discuss the material they had gathered. Twenty three stories were generated in the first round. Most of these came from people who used services in the area or who lived in the area and worked in services. The process of gathering stories itself had a big impact on the story gatherers. They described some of the stories as '*heartbreaking*'.

2.14   In late June 2009, we met with the Hub to analyse the first round of stories. Hub members were given time to read all the stories and to talk about their response to them.   We explored what they found positive in them; common themes and differences across the stories; the challenges they presented and the implications for actions. We also considered what and who was 'missing' from these stories.

Story round two - filling gaps and furthering inquiry

2.15   As Hub members began to identify what they were learning, it was decided to select a sheet of key quotes from the stories and from their discussion, to be used as a prompt to generate further discussion amongst their colleagues and other community members over the next 6 weeks. At that meeting we also identified gaps in the information. More stories from men were needed, from those aged 35-60 years old and from community members who weren't using services at all.

2.16   On 11 August we had a final meeting with story gatherers.   They had collected a further 20 stories, several of which had been gathered during an afternoon standing in the shopping centre. This had been particularly successful as the story gatherer was very well known in the community.

2.17   Two further meetings with the Hub were held. The first in mid August when Hub members reviewed the new set of stories and again, analysed their response to them. After that meeting the facilitators continued the process of analysing the themes, which were being generated and the Hub developed further actions from this new list of themes at our final meeting in early October 2009.

3 Learning from the stories of Langside and Linn

3.1 The story gathering process has brought together a total of 43 stories from local people. The stories are honest and compelling. The process took time and, at times, was difficult, because of the nature of the stories. For story gatherers and those that heard the stories throughout the process, the process was a refreshing and powerful alternative to collecting information through surveys and similar means. In the words of the participants, it was an unexpected 'reality-check'.

3.2 A review of the titles given to their stories by the tellers alone gives a strong flavour of their content. We have not reproduced all the stories here, but this selection gives a flavour.

"One way for one person, different for another" suggests that whilst some families get excellent support from health services, others don't. Some people don't know who to phone or where to go.

"Mixed up seizures-nasty Doctors" appeals for greater awareness of epilepsy. It's a story of a struggle to get the medication right and an appeal for people not to jump to conclusions about people with the condition.

"*Falling on deaf ears"* was told by a middle aged woman from Castlemilk who was surprised that we valued her story. She said '*people palm you off when you come from an area like Castlemilk*'. Her story told of the legacy of drink problems in her family, which meant that she does not drink herself. She said '*Doctors generalise here – they think that because you are from this area you will be a heavy drinker. Once when I had a stomach compliant, the GP said 'you'll have had a heavy weekend with the drink then?' It may have been a joke, but that's how it is lots of the time. When I say I don't drink they are lost for words and have nothing useful to say to me. My experience is they're not interested and have usually made their minds up before you speak. It doesn't help'.*

"Not supported" is about dealing with depression over a long period of time and feeling let down by services that prescribe anti-depressants and little other forms of support.

"*Same choices for everyone even mental health patients"* is from a carer of a man with schizophrenia. She talks about them '*being patronised'* by the Community Psychiatric Nurses. She says '*the new rules are that he has to be kept in the community, but sometimes that's too hard and I need a break. It seems to come down to who you see. Some carers and patients have great relationships with CPNs and they support both the carer and the patients'*

needs. Other people just don't seem to get this. You can ask for a new one but not everyone knows this'.

"Life alone" was told by a young man from Castlemilk and talks about his friends who have alcohol problems which are affecting themselves, their friends and their families. *'My friend spends every penny he has on alcohol, rarely buys food and is very thin. He doesn't keep well. He lives with his Mum who suffers from depression, which makes him drink – just to get away from it all. He has no aspirations, he has low self esteem, no confidence – his mental state isn't good and he has tried to take his own life'.* He wants his friend to get help and support and to know where to start accessing what's available.

"Dads drinking" was told by a young woman from Kings Park & Mount Florida, who talked about the impact that over 20 years drinking has had on her father and their family life. *'Alcohol has lost me my Dad that I once knew, and left us with someone we don't recognise anymore. He has lost all his other family because they refuse to speak to him; he's only seen his grandchildren once or twice. When he refuses help there's nothing anyone can do but watch his life waste away'.* She'd like health services to offer more informal help to addicts who have shut themselves away from others.

"Rugby Club" is also about alcohol, but more positively suggests that some people are more aware of the damage to health and drink more responsibly than they once did. It was told by a retired man from Kings Park & Mount Florida who talked about greater awareness of drink driving limits amongst people at the Rugby Club; *'most people I associate with are aware of their health and wellbeing and take responsibility for themselves. People like us don't have problems and if we did, we'd be able to ask for help for them'.*

"To be treated as an individual" was told by an elderly woman. It tells of the difficulties of accessing services. *'I feel it is hard to access services as GPs can be reluctant to refer you. It has taken away my confidence. I don't want to go to my GP now if I have a problem. I will put up with it rather than go for help. I felt my GP was very off-hand with me.   At my age, I need to be careful. If there's a problem I would like to get some support, advice and reassurance from my GP that he is doing everything possible to find out what is wrong with me. I want him to treat me as an individual and not one of many'.* She said that telling her story had helped her to get the issue off her chest and that she felt better able to discuss the situation.

"I was completely traumatised" is about the experience of a middle-aged woman for whom an apparently 'minor' operation at the GP surgery had bigger and unanticipated implications.   When asked what changes are needed she suggests that patients need to be better prepared and should be more assertive in asking more questions. She says *'there needs to be clearer guidelines, checks and standards for GPs and any treatment needs to be logged*

and followed through, so the GP is accountable. Evaluations should be given to clients to give feedback on their experiences – this should be collated and used to inform the NHS to help set and improve standards'.

"Flexibility & choices" is an appeal for more staff training for those that work in GPs surgeries so that they can be flexible and sympathetic to people's needs and better able to recognise the needs of carers.

"Children's rights" was told by a young man under 16 years old, from Castlemilk. *'In my experience a lot of rights are continually ignored as many teachers don't respect our opinions and often undermine the confidence and intelligence of many young people. There is a lack of awareness of where to go to ask for support'.*

"Scapegoat" takes a similar theme, and is about feeling unfairly treated at school, with no redress. This was told by a young woman, under 16 years old, from Castlemilk.

"Being pushed from pillar to post" was told by an older women, with multiple health problems, from Langside & Battlefield. *'It takes months to do the different tests for each illness, and I'm still left feeling the same way It's taking too long to find out what's causing my problems and I'm feeling frustrated. I'm treated like a number, not as an individual'.*

*"Diagnosis, depression & death" i*s told by an older woman who is now a volunteer in her community. She strongly advocates that people should get a second opinion. Her story tells of spiralling health problems, misdiagnoses and a premature death in the family. It shows the impact of physical illness and mental health amongst wider family members, many years after the initial problems.

"Daughter's depression" describes a family struggling with the mental health problems of a teenage girl. It reports a catalogue of difficulties with services and a lack of support over many years. Support is now in place is and is much appreciated.

"Ten years of death" is another story of medical issues from a young age spiralling into mental health and family problems. A history of a lack of support from professionals has been belatedly addressed today by support from the voluntary sector.

"Uncomfortable in A & E" is from a young man who had an accident and had to go to A & E on his own. *'I'd like the waiting area to be friendlier for young people'.*

"Worrying time" is told by the wife of man with heart problems, now discharged but with no follow through, despite her efforts. She still wants an explanation to give her '*peace of mind'.*

"No time for the sick" was told by a middle-aged woman from Castlemilk. She says *'my Doctor's motto must be 'heal thyself' because you can't get much out of them. If you are prescribed something and it helps, you are taken off it again. It's like trying to get blood out of a stone. I have even been in tears and still came out with nothing'.*

"Moving on" appeals for more support for ex-drug offenders on their release, to help them get out of the cycle of offending.

"Neighbourly care" tells about an incident when a middle aged woman tried to deliver some flowers from church to a local nursing home. She didn't feel welcome by the staff, although the residents did seem to appreciate her visits. She thinks that *'more visits from volunteers would improve the ambience of the home.'*

"Lifeline" is a positive story about the value of support from voluntary sector services, without which *'my family life would have been more difficult and isolated. It has given me confidence and helped me to relax. There are a lot of supports available and people need to be aware of this'.*

"Support for all" is about the need for everyday support, told by a woman who's lived in Castlemilk for nearly 20 years; *'you shouldn't need to be in crisis or labelled [to get support]. People in the community today appear to feel let down by services and feel you need to have additional problems to access services. Families in general need support!'*

"Loneliness" is told by a volunteer in the community with firsthand experience of the loneliness and lack of confidence of elderly people. *"Befriender"* is similar, but also tells of the benefits of befriending, for the volunteer, who may themselves have health problems; *'offering companionship is a way to maintaining my own health'.*

"Older people's services" is told by a young person about their family: *'My grandparents don't have much to do in my area – he sits there and watches TV. There should be more available for older people so they can be fitter, healthier and live longer'.*

"Here, there and everywhere" is about coming home from hospital and the issues with patient transport. *'The ambulance service brought her home and after carrying her up the first steps, left her for myself to get her up the rest of the way. We also have two internal stairs that took up an hour to get her up! I could not cope and my wife ended up back in hospital. This had a terrible effect*

on me – not be able to care for my wife. There are also issues about getting patient transport to appointments. Lots of families get calls on the day saying there is no transport, so their appointment will have to be cancelled – but some hospitals record this as 'patient did not attend'. Once we were told that patient transport can only take the patient and not the carer – even though it was a taxi and had room!'

"Surviving and hope" is about being treated for cancer and is full of praise for the hospital doctors and the other patients – who were a source of strength. *'The NHS is the best thing in the world. You get some grumpy staff, but grumpy patients too. I can't speak more highly – I don't have words for it'.*

"Healthily Surprised" is about being taught something useful; *'my 21 yr old nephew taught me something useful about my health. He said 'do you know how to test yourself for testicular cancer?' I was a bit surprised and laughed but he showed me how to do it. Later I did find a lump although it came to nothing. When I was younger you didn't have all this information and you didn't talk about anything serious to do with your health with your family or friends'.*

"Stopping Smoking" is about a 15 year old young man who wants to stop smoking. *'I found out that chemists have been retrained to support us to quit smoking'.*

"Hospital aftercare 4 out of 10" is an appeal for greater support to get mobile again after an operation.

"Yawning Doctor" was shared by an older man from Castlemilk. *'The Doctor was too busy yawning – yes, yawning. They were not interested in me and I left very angry. After I'd left, I realised they'd not given me a prescription I wanted and I had to buy it, although it would have been free'.*

"Receptionist rules the roost" is another story about a younger man going to the GP. *'I don't feel comfortable - the receptionist rules to roost – she can tell you about your health before the Doctor. She must look at your records. I know that others feel the same - where is the confidentiality?'*

"Blood will tell – sometimes too much!' is about a man who found out he had Hepatitis C after he'd made a Blood Donation. *'I've had to make lifestyle changes and I'm no longer involved in reckless drinking, which I did do in the 1990s. The future is uncertain. I still feel the stigma surrounding my disease and wish it was better understood by the public'.*

3.3   Other stories have not been given titles, but they pick up similar themes. They talk about services not providing the help that people want; of families not talking about health issues, with longer term implications; of things going wrong in hospital. There are stories about difficult health messages not

being delivered with sensitively or with thought for how people will feel. A summary of the themes and story titles is given in Annex 1.

4 Analysis of the stories

4.1 The stories were discussed by the story gatherers themselves and also by the members of the Hub as detailed in Section 2. Some of those who were at the discussions of the stories had also been involved in the collection process. The act of sharing stories in this way also sparked off further stories from the Hub members.

4.2 The Hub were pleased that local people had been prepared to share such personal and poignant stories and felt they would not have got the same information through a questionnaire:

> *"This is completely refreshing in the sense of how powerful [it is] in people's own words. It is reality and we can't dispute [that]....people have been so honest about their experience, which in itself is really powerful".*

What's working well?

4.3 It was said to be positive that the feedback illustrated that some things were working well:

> *"Some agencies are identified and people are actually using them - and they seem to have had good experiences, so clearly we're doing something right! That's nice to get back. There's a lot more to be done. But there's a glimmer of hope in there."*

What's not working well?

4.4 However, despite some positive aspects of service provision, many stories illustrated experiences that were at odds with professional assumptions about how people would or could access services:

> *"The stories are similar – they are saying the same things in different ways – services are out there, but they are not using them."*

4.5 There was a sense that: *"something's not quite right - services aren't working".* This opened up a discussion about the reality of professional attitudes and inter-agency working:

> *"Are services not talking to each other? We're so busy doing what we do".*

"The professionals in the stories know that things are wrong...but they tick their boxes and may be thinking 'is it my remit?' They do know what's going on – but think 'it's not my problem'."

"What's been surprising is how much has focused on the social and how few expectations we have of GPs".

"There's no directory [of local services] –we don't know who's still functioning".

4.6 The story process helped to show to those involved that they themselves hold assumptions and preconceptions about services (whether they are aware of them or not) that may act as barriers to change. The discussions suggest that there is a need for better awareness and better cohesion or integration of services, but it is not clear how existing remits and roles support integrated services, including that of the Health Forum itself:

"As long as you tick your box then you're fine....but what difference are you making to quality of life?"

Getting heard and being listened to

4.7 Both Hub members and story gatherers found that some stories were '*difficult to hear*';

"I was quite struck by how severe, how upsetting the stories are.....and that sadness is concentrated in Castlemilk. The depth of issues and depth of pain.....it's quite palpable".

There is a theme in the stories about the real difficulties people encounter communicating well with service providers, in particular with their GPs.

"People who are less affluent- seem to find it difficult to get heard."

"There's quite a lot about health professionals and how they haven't really measured up in this area – which is something worthy of addressing".

4.8 The difficulties of confident self-advocacy were also evident in some of the stories from young people:

"There's lots in there about young people not being heard".

"From the young people's perspective...they know they have rights....but they're not able to assert them....they're stymied in effect."

"Issues of confidence, not being able to assert yourself with GPs etc seems to start in school...."

4.9   Some people are able to be proactive and assertive. Others are not skilled in asking for what they want and may be aggressive.

"There's a fear out there of challenging those 'up there' – there's still that fear that if you dare to say to your GP 'I want another opinion' then you might be, what's the word? - 'stigmatised' - for speaking out. I'm not scared, but people are!"

"I had to ask for a medical check up – I wasn't offered it."

"Some people are not necessarily assertive with their GPs – they're aggressive."

"The way GPs react when men actually do speak to them appals me".

"Professionals are not evil – GPs and others are very pressurised – it's something about the system".

4.10   These issues of advocacy raise interesting questions about how the Health Forum can 'give voice' to local people and support GPs and other professionals to manage their time efficiently without alienating people. Some of these stories may be hard to share more widely; many are very critical of services that Health Forum members know to be under great pressure. It will be a challenge for the Health Forum to share the learning in a positive spirit.

The role of GPs and access to services

4.11   The stories also raise some challenges to assumptions about the respective roles of GPs and the voluntary sector. They show that the general population have a largely 'medical model' of health, rather than a social one. Given this, they naturally see their GP as a first port of call, whereas much of the work of the voluntary health sector is based on a very different assumed pathway to services:

"One of the assumptions that has been challenged by this is that whole idea that your GP isn't necessarily your first point of contact - or shouldn't necessarily be. If you think about statutory services and where they fit in - lots of things should happen before you end up in the GP's surgery. Are there some different assumptions in this about what GPs, statutory services and voluntary sector should all be doing?"

> *"To me the stories are saying, 'yes you've got your GP, but you need other alternatives'......the GP's not always the best one for you".*

4.12   There were discussions about what works well to encourage an easier pathway between GPs and other services designed to support health and wellbeing:

> *"The Stress Centre get more referrals when they are actually working in the Health Centre".*

> *"There's positive change happening, for example, increases in the use of the GP exercise referral scheme".*

4.13   There was also comment that GPs may be *".... unwilling to refer [to the voluntary sector] because of short term funding."*

Too much or more coping?

4.14   There's an issue underlying many of the story themes about how services can work to support resilience in communities. Resilience is the ordinary capacity of individuals and communities to 'bounce back' after a crisis or episode of illness, or simply the ability to cope with the daily challenges of 'getting by' on a low income.

> *"There's something about building resilience. It's quite intangible, but there's overreliance on going to the GP and getting anti-depressants, rather than thinking about alternatives and ways to cope other than using prescribed drugs. You could have the same conversation about alcohol or smoking -people are leaning on these things in the absence of something else".*

> *"Drugs are used as a coping mechanism – there are very high prescribing rates for anti-depressants in Castlemilk and people expect and desire that.... people are disappointed when they don't get anything from the GP".*

4.15   Resilience is usually seen as a positive attribute and source of pride:

> *"I was interested in the Rugby club story - he was clearly saying 'if there's something wrong I know how to sort it'."*

4.16   Getting by or coping is ordinary and common place in areas like Langside and Linn. There are many examples within the stories documented here.

> *"Communities will support each other – if you give people the skills to do it. That story about the young person who realised their friend was drinking quite a lot. It does happen, but how do you build on that?"*

4.17   There may also be potential to learn from those who have understood the health messages and are more self-reliant.

4.18   It is clear that many of the ways in which people cope create new health issues and that some have become embedded in the local culture. But a slightly different angle on the issue of resilience was raised during an exchange in one of the discussions:

> *"Is there too much coping? You're supposed to cope...."*

> *"I don't think there's too much coping. I think there's too much of pretence of coping. Nobody wants to be seen as being weak or needing help. Nobody wants to be seen as a bad parent, teacher or health professional. Rather than stand up and say 'I can't help you' they maybe find things.....but, they aren't focused interventions....it makes sense to be 'doing something'."*

4.19   This acknowledged that 'coping' or 'being resilient' was also an attribute of professionals and volunteers who work in this area. This was powerful and resonant amongst those present. These issues are rarely acknowledged and the quote suggests that one strategy may be to appear to know what to do, (usually more of the same) whilst not necessarily being as effective as would be wished.

4.20   A challenge to service providers would be to think more about how the way that they work enhances positive resilience:

> *"People are not skilled and trained to ask for a second opinion for themselves. We're support agencies...but we're not necessarily about supporting people to build that [confidence] for themselves".*

4.21   When presented with a need there is often a temptation to go straight to a service-based solution. So if people are isolated and lonely, what they need is a befriending service, rather than to offer and receive friendship. This latter perspective might lead to them becoming volunteers or engaging in some other activity in which friendship is a spin-off.

4.22   It was acknowledged in the discussions that one of the strengths of the area, particularly Castlemilk, is that *"residents have great connections and staff live here too – this is a real asset that is distinct to this area. There's pride in Castlemilk – people rally round".* At the same time a barrier to service access was said to be: *"there aren't enough well-known and trusted people to help*

people access services (a well-kent face)". So there does appear to be scope for making better use of these local networks to reach out to those who are disconnected from formal or mainstream services. There must also be scope for linking up with other networks such as community-based housing associations.

Information and awareness raising

4.23   Networks may offer other means of getting information out more effectively.

> *"Where can people get the information they don't get from the GP? What use can we make of less obvious routes?"*

> *"Parents don't know what to do about bullying. A Health Spot referral would be a start....but they don't know that".*

4.24   The discussions suggest that making the best use of networks requires investment in relationship building to enable not just the issuing of information but the sharing of knowledge and the testing of understanding. And this will need to be a continuous process. Health Forum members acknowledged that published information is soon out of date; communication is better face-to-face.

> *"We do send information to Health visitors (and other mainstream services) by email – but they've no time".*

> *"Staff in GPs who've been there a long time know about us, but newer ones don't."*

> *"We asked to meet with a GP and were told 'you've more chance of getting a meeting with the Pope!'"*

4.25   In many ways, the story gathering process illustrated the benefits of simply being proactive and going out and talking to people.

Systemic issues and unintended consequences

4.26   Stories are really useful in highlighting systemic issues and the unintended consequences of policy and practice. For instance many of the stories illustrate the linkages between physical and mental health:

> *"There's lots of issues around mental health – it's threaded through just about every story. And is often rooted in physical or medical issues – maybe a long time ago".*

4.27 This demonstrates the holistic nature of health and wellbeing and the importance of the way that the system deals with people. Apparently mundane issues about the way that people are dealt with when they first encounter a service, can have much larger and long term consequences. Even something like way that messages are conveyed about not missing appointments in GP surgeries can have the consequence of conveying a subliminal message that the doctor's time is not to be wasted. In one story, this caused the patient to be flustered and forget all the things they wanted to ask. This is clearly not the intention, but is does illustrate the wider implications and shows how practice management can become a barrier to access:

> *"Waiting rooms are off-putting – there is a pressure because GPs time shouldn't be wasted".*

> *"Admin staff are used to protecting GPs – there are good things happening – training improves their practice. But, they are rarely trained in anything that's not about [administrative] systems."*

4.28 Patient transport is also an example of an blockage that has unintended consequences elsewhere in the system and shows that the most effective focus of intervention in health improvement may not necessarily always be the most obvious one:

> *"Patient transport is a real issue – for example, it can't take carers; it sometimes doesn't turn up. Appointments aren't cancelled because the transport is not available but people don't show up."*

Health Forum, agency and service responses to meeting needs and resource issues

4.29 The insights from this process clearly raised a number of challenges to the members of the Health Forum about their role, and how the Forum fits into the larger strategic picture:

> *"There's all these different meetings going on if you know about them....like the safety forum? Yes, but there's no cohesive knowledge – there's something lacking - isn't that what the CHCP is supposed to do?"*

> *"There no social work rep at L & L HF – don't think they're even on the mailing list?......Theoretically structures are in place – but what about the practice? The Health Forum is OK, but what about the Safety Forum, Volunteer Network?"*

4.30 Funding and governance structures tend to support 'service based' perspectives and cultures with different agencies in competition with each other for funding and potentially also clients. It was not always clear to the

Hub members what action they might take to shift out of this service centred perspective. 'Funding' was described as the 'f-word' and even if there was more available to 'do something' – which it was acknowledged there is not, the discussions did not suggest that that would necessarily be better;

> *"We are never going to be able to provide all of those things for people that need it. There's something about resources and us being realistic. There will be a prioritisation".*

> *"What could be done that's more modest?"*

> *"We can't wrap everybody in cotton wool. Nor should we."*

> *"We're learning something from this about what services don't have to do – as well as what services do".*

4.31   This dialogue raised many questions amongst the Hub members and, in many senses that was its value. Hub members started to ask about what should be done differently and raised questions about the role of services, how they could be more collaborative; how they could work to encourage personal responsibility; they expressed concerns about raising expectations and demand by publicising services that do exist; they began to think more widely about health improvement planning, particularly in relation to the new Health Improvement Plan under consultation at the time of the research – and saw stronger links with Primary Care. They became more interested in evaluation – perhaps not as conventionally practised but as a way of getting feedback and acknowledging and celebrating success.

Learning from the story gathering process

4.32   The Hub were also very reflective about the process itself and its strengths and limitations. There was a lot within the stories about barriers to access to services, including such things as lack of trust in confidentiality, fear of wasting time, the attitudes of professionals, and structural barriers such as eligibility for patient transport.

4.33   In asking people to share stories we had taken the decision to ask them to 'self-categorise' (Annex 2) in relation to conventional 'equalities groups' in terms of what they thought was relevant to our understanding of their story. Age, gender, disability and faith group were the only categories offered in this way, indeed a second round of story gathering used this information to target stories from 'under-represented' groups. Whilst the process may not have been consistently applied because of the informality of the method, no one self-identified as being from a black or minority ethnic community, LGBT or as having literacy problems. In discussing the reach of the research, the Hub members could see that discrimination also takes the form of an

'invisible barrier' which serves to exclude in ways that are not acknowledged;

> *"Are we missing the people in the middle... are they just coping? They're not easy to categorise...but that's part of the problem....there's a huge amount of the population that none of us are targeting."*

4.34 Ultimately the reach of the research partly depended on the profile and efforts of the story gatherers; who you are limits or extends who will talk to you. It was acknowledged that '*it would be easy to use this technique with other communities such as black and minority ethnic communities',* but only if story gatherers are recruited from those communities. This issue is developed further below.

5   Conclusions, recommendations and on-going inquiry

> *"It is better to begin by acknowledging that you <u>think</u> you know, but best to <u>assume</u> that you really do not.[9]"*

5.1 The value of using an action research methodology based on story gathering by local people and local professionals was continually remarked upon by Hub members and story collectors. In terms of learning, we are confident that it has been more effective than a training course or consultancy change project because the learning was 'contracted in' to the approach. This has modelled a process which has the potential to become a 'way of working' within the Health Forum and with partner agencies.

5.2 The process has challenged the assumption that the problems of change at the local level are primarily about a deficiency of evidence, deficit within the community or unwillingness of people to share their stories or get involved – this process shows that they do care and will share if asked in the right way. This kind of useful feedback enabled existing services to gain a better understanding of what they are good at and what they need to improve. It also helped them to have better intelligence about who is using their services and who isn't.

5.3 The limited 'reach' of the research (using service providers & local community members) also mirrors the reach of the services - this seems to be a lesson for services too. In the research, our approach to sampling didn't seek to target equalities groups, although we were constantly mindful of the profile of those who were sharing their stories as the process unfolded. The design of the process was such that it should be accessible to everyone – what happened was that we mirrored services ability to access, except when

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[9] Paul Bate and Glenn Robert (2007) *Bringing User Experience into Healthcare Improvement. The concepts, methods and practices of experience-based design*, Radcliffe, Oxford. p38.

a deliberate decision was made to seek out those people who were not so readily accessible or completely unknown to the story gatherers. The decision by some of the story gatherers to do this by going to the local shopping centre and setting up a stall there to interview people, assisted by the involvement of people who were well known in the community, enabled them to access a whole range of other story tellers and demonstrated that people are prepared to talk to people they feel comfortable with. This suggests a challenge for services to be more 'culturally competent' in recognising how they engage with people, the questions they ask and the information they give. A more regular process of seeking and giving feedback through some kind of collective 'story-based' process could enhance the development of this competency amongst individuals and strengthen the role and impact of the Health Forum.

5.4   Although the wealth of existing indicators on health and social care do illustrate the inequalities in and between areas, this research serves as a modest illustration of how the 'inverse care law' actually operates; the inverse care law states that *'the availability of good medical care tends to vary inversely with the need for it in the population served'*[10]. Other research shows that:

> "The increased burden of ill health and multi-morbidity in poor communities results in high demands on clinical encounters in primary care. Poorer access, less time, higher GP stress, and lower patient enablement are some of the ways that the inverse care law continues to operate within the NHS and confounds attempts to narrow health inequalities"[11].

5.5   Whilst this research was not designed to be an investigation of primary care, many of the substantive findings do illustrate the 'human narrative' and the dynamics of inter-personal effectiveness in encounters between people living in deprived areas and health care professionals, including, but not exclusively, their GPs. Mercer and Watt's research suggests that the interpersonal relationships aspects of care are as important as the technical; patients have better outcomes in reported symptoms and wellbeing after consultation where their GP is empathetic[12]. Annex 3 contains more information about this research. It is also worth noting that an evaluation of the effect of increasing consultation length on patient enablement in general practice at the Keppoch Practice in Glasgow had positive outcomes; it demonstrated improved patient enablement and lower levels of GP stress,

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[10] *Stewart W. Mercer and Graham C. M. Watt, The Inverse Care Law: Clinical Primary Care Encounters in Deprived and Affluent Areas of Scotland,* Annals of Family Medicine, Vol. 5, No. 6 November/ December 2007

[11] As above

[12] Stewart W. Mercer and Graham C. M. Watt, (2007) as above.

more opportunistic screening during consultations, greater exploration of mental health and psychosocial problems, more systematic management of long term conditions and greater liaison and referral to other agencies to support the non-medical aspects of health and wellbeing[13].

5.6   The process of analysing and reflecting on the themes generated by the stories led Hub members to make a series of recommendations, which are included below. As might be expected, in the true spirit of action research, the process generated a good deal more questions. As facilitators, we think it has been an enlightening and positive process. It has been a fairly modest piece of work in terms of time and resources. It was informative that the Hub members did struggle with crafting appropriate actions that they could see *they* could take. This difficulty in 'finding the action' has been noted in other action research:

> *"Expectations regarding action may differ considerably and smaller, achievable, personal or local actions may go unrecognised".[14]*

5.7   In a process of longer duration, it would be possible to explore this more fully; to take time to craft and test out what Hub members *could* do and what the opportunities and constraints *really* were when tested out in this way. This would address the questions about what Health Forum members see as their purpose and role. We are also confident that there would be benefits in enhancing the clarity of purpose and accountability of the Forum.

5.8   As facilitators, our main recommendation to the Health Forum is that this process should continue as an embedded part of how the Forum operates[15]. And It is important that the process does not lose momentum and that the energy and enthusiasm of the participants in this process heralds the start of a new way of working. This could enable the Forum to identify the health issues that really matter to local people, and continue reflecting on the best ways to tackle these.

Adopt action research as a way of working

5.9   Our recommendation that this approach should become a 'way of working' for the Hub echoes their own enthusiasm that they should continue to share and learn from best practice.   Such an approach would give them the

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[13] Stewart W Mercer, Bridie Fitzpatrick, Glen Gourlay, Gaby Vojt, Alex McConnachie, and Graham CM Watt, *More time for complex consultations in a high-deprivation practice is associated with increased patient enablement*, British Journal of General Practice. 2007 December 1; 57(545): 960–966. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2084135/

[14] Reid, Collen; Tom, Allison & Frisby, Wendy (2006) *Finding the 'action' in feminist participatory action research*, Action Research, Vol 4, Issue 3, Sept 2006

[15] This does not need continuing external facilitation.

structure and tools to explore the successes, problems, contradictions, assumptions and prejudices in the organisations and communities in which they work in order to find new practical ways of acting. It also has the potential to draw in others as it proceeds and to strengthen partnership working.

Explore the links with co-production

5.10   A co-production approach to service design and delivery brings the kind of individual, family and community knowledge highlighted by the stories into the shaping both of resource allocation and of the strategies deployed to deliver health and wellbeing outcomes.[16]   Co-production is an on-going process, not an event and relies on the kind of on-going inquiry that is demonstrated here. We recommend that this action research approach is considered by the South East CHCP as a way of moving further towards services which are truly produced within communities and make the most of natural resilience and supports.

Build on what's working well

5.11   The Forum wanted to see a more 'appreciative' approach to their work in order that good practice is recognised, rewarded and shared. As this research has shown, this is a good starting point for inquiry. This includes the need to be better at on-going self-evaluation and feedback. Their recommendations were:

> e) The Health Forum should develop a baseline for good practice and get better at capturing the difference we make (through the use of story telling among other methods).
> f) The Health Forum should review what we are learning on a regular basis.
> g) The Health Forum should ensure that community members get feedback about changes being made as a result of their contributions.
> h) The Health Forums in the area should get together regularly to share and celebrate good practice.
> i) Funders, in particular the CHCP should invest in things that are working well over the long term.

Tackle what's not working well

5.12   Much of what was not working well centred on how people found out about and accessed services. Hub members made a series of recommendations aimed at enabling services to improve their practice:

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[16] For further information cf. Coproduction: a manifesto for growing the core economy: new economics foundation (2009)

j) Services need to strengthen partnership and build on the networks we have – the Health Forum has a role to play in facilitating this.

k) All services should improve their marketing and aim it at particular audiences eg. parents

l) Services should make more use of 'well-kent' faces to reach those people in the community defined as 'hard to reach'.

Promote access and confident self-advocacy

5.13 Part of the learning from the process is that the way that services are provided sets up barriers that exclude people in ways that are not easy to see, categorise or anticipate. In practice, many people do not self-identify themselves as belonging to a particular category or group. The original brief had a strong concern about all the six 'Fair for All' equalities strands. The stories illustrate many examples of assumptions being made about people that have acted as barriers to communication and ultimately to services.

5.14 Hub members discussed how they could let other professionals know about the struggles community members had in putting their views across and accessing services and how they could make services more responsive to individuals to improve inclusivity and access for all groups. This suggests the need for a more explicit leadership role for the Forum. They recommended that the Health Forum should:

m) Work with the Medical Director at the CHCP to inform GPs both about community members' experience of the service in Langside and Linn.

n) Inform other partners about the issues identified through the research, for example, social work and PACT.

o) Continue the work of building relationships between professionals so that information is shared in a meaningful way.

p) Publicise the breadth of health and well-being services available in the community.

5.15 There are also some more service-specific issues and barriers that the research highlighted that the Forum should investigate further. They recommended that the Forum should:

q) Investigate whether GPs really are unwilling to refer people to community based services because of short term funding, and if so, what can be done about it.

r) Ensure that the Stress Centre can operate out of the Medical Centre on a more regular basis.

Tackling systemic issues

5.16   One of the advantages of collecting stories from service users in this way is that it gets at the *'experienced reality'*, highlighting issues around partnership working by illustrating how complex, cross-cutting services work in practice. Several of the issues highlighted in the stories including patient transport and experiences of administrative staff in GPs surgeries, pointed to underlying problems in the system which had an unwelcome 'knock on effect'. Hub members struggled with how to tackle these since they seem to be outwith their direct influence. In the first instance they recommended that the Forum should:

   s) Use structures within the CHCP to ensure that issues such as patient transport are tackled by those responsible for them.
   t) Use the story gathering process to keep identifying these kinds of issues.
   u) Encourage services to have systems for gathering feedback eg. boxes in surgeries.
   v) Examine coping as an issue both for community members and professionals as part of the health and wellbeing strand of the Health Improvement Plan.

Support Community Resilience

5.17   Hub members recognised that the natural strength of a community like Castlemilk needed to be built upon and nourished, and that issues of dependency on services needed to be challenged. Again it was a challenge to identify ways of doing this. They recommended that services should;

   w) Recognise, value and build up pride in the community in whatever way possible.

Continue inquiry: questions for further exploration

5.18   There are a number of issues or questions raised in this course of this research that we believe warrant on-going and further exploration. Some of these have been flagged up in the specific recommendations above and others have been identified in subsequent discussions with the Health Forum. Figure 5.1 below summarises these. Some of these are short term issues, others will require a more sustained and long term approach. All involve the Health Forum as a starting point, drawing in other key stakeholders including the South East CHCP, the NHS, the Public Participation Forum, Primary Care representatives and GPs, other community and voluntary sector partners, specialist youth or other representative groups and wider Community Planning Partners. This illustrates the pivotal leadership role for the Health Forum in developing partnerships and

improving communication between agencies and with the public to support health and wellbeing outcomes. It is our hope that this research and the approached adopted is just the start of continuing action-focused inquiry.

Figure 5.1 A summary of key on-going inquiry questions

Partnership working and good practice
a) How can the voluntary sector and primary care sector work more closely together to improve services?   b) How do we encourage statutory and voluntary sector partners to be better represented at appropriate meetings and fora?   c) How do we build upon successful processes and structures that promote good practice?   d) What actions should be undertaken to support sustained funding for voluntary and community organisations?
Resilience
e) How can we build resilience and confidence in our local people?   f) What role do local networks have in building resilience?   g) What does it mean for services to focus on building resilience for individuals, families and communities?   h) Is there further work worth exploring on supporting local people to find ways of coping that are not detrimental to their health?   i) What does 'pretence of coping' mean for organisations and professionals and the services they provide?
Promoting access and self-advocacy
j) How can we encourage public services to always treat individuals with respect and as individuals?   k) How can we encourage individuals to act in assertive ways with services rather than being aggressive or accepting of inadequate service?   l) How much conscious social support can the Forum offer /build into its (collective or individual) services and activities offered locally?   m) How can we specifically address the issue of young person friendly health services?
Promoting the 'social model of health' and understanding of rights
n) Can we get the general population to value other services and think through their "first port of call" more effectively?   o) How can we support the general population to be more aware of their rights when accessing health services?   p) How do we market services to increase awareness and accessibility?
Service –specific issues
q) How can we feedback our findings about professional behaviours in a positive spirit?   r) How can we investigate whether GPs really are unwilling to refer people to community based services because of short term funding, and if so, what can be done about it?

s) How can we keep GPs up to date on options for referring patients to voluntary sector services?
t) Can we ensure that the Stress Centre can operate out of the Medical Centre on a more regular basis?
u) How can we tackle the issues raised regarding patient transport including missing pick-up slots; not taking carers; difficulties with the booking arrangements?
v) How can we enhance environments such as GP waiting rooms?
Monitoring and evaluation
w) Can we use story gathering to help monitor and evaluate local initiatives and projects?
x) How can we include people such as people from a BME background; LGBT community; people with disabilities?

Annex 1: Additional information about the stories

Theme number & title of prompt card	Number of times selected	Selected titles of the stories – all given by the story teller
1 Agencies involved in making decisions about service delivery are working really well and are really listening to local people	4	*One way for one person, different for another* *Young people are listened to* *Mixed up seizures-nasty Doctors* *Falling on deaf ears*
2 People with mental health issues feel supported and connected in their community	3	*Not supported!* *Same choices for everyone even mental health patients*
3 People are not drinking in ways that are harmful to themselves and others now and in the long term	3	*Life alone* *Rugby Club* *Dad's drinking*
4 Local people have better health because they have more influence over services and activities	3	*To be treated as an individual* *I was completely traumatised* *Flexibility & choices*
5 Pupils will know where to get impartial support about their rights as a child in the education system and wider society	2	*Children's rights* *Scapegoat*
6 People are informed of their rights regarding confidentiality when accessing sexual health provision	0	
7 People will know where to go for support and guidance when experiencing multiple health and well-being issues	2	*Being pushed from pillar to post* *Diagnosis, depression & death*
8 Men are aware and taking responsibility for their own health	0	
9 Ex-offenders are being supported to build their lives positively in the community	1	*Moving on*
10 Young people are supported on their own individual health issues which gives them confidence to move forward	2	*Daughter's depression*

11 People are more confident and feel part of their community	0	
12 People recover quickly on leaving hospital because they have good support in place	3	*Ten years of death* *Worrying time*
13 Older people have their health and social services delivered as appropriate to their individual needs	1	*Neighbourly care*
14 Families feel supported and connected in their community	3	*Lifeline* *Support for all*
15 Older people are socially active and included in the community	2	*Loneliness* *Befriender*
16 We make the best use of informal opportunities to talk about health and to learn what matters to people	2	*Talking about health*
Not connected to a numbered theme	n/a	*Older people's services* *No time for the sick* *Here, there and everywhere* *Surviving and Hope* *Stopping Smoking* *Headlight* *Hospital aftercare 4 out of 10* *Yawning Doctor* *Receptionist rules the roost* *Uncomfortable in A & E* *Blood will tell -sometimes too much!*

Annex 2

Langside and Linn Health Forum

Story Gathering Research
Story Collection Sheet

What this research is about

We are volunteers who are collecting stories on behalf of the Langside and Linn Health Forum. We're talking to people who live or work locally and who are prepared to talk to us about their health and wellbeing. Over the next few months, the Health Forum will be actively using these stories to influence services that support health and wellbeing in this area.

We want to hear about the experience you have had: the good bits as well as the bad, so we're doing this in a different way to usual. In a moment, I'll show you some prompts to see if they trigger off a story. But first I need to ask for some basic information.

Our commitment to your privacy

Please go through the following points with story tellers.

a) Your story will be anonymous. This means we will not use your real name in connection with the story and will make sure that you cannot be identified from any of the details in the story.

b) We may want to check back any details of the story with you. We need some way of getting back in touch with you in case this is necessary. This information will be confidential.

c) If you want to get back to me after today with any concerns or issues about your story please get in touch with me. [Give them a suitable contact number]

Basic details

Please complete all this information below before starting.

Name of story collector
Name of story teller
Best way to contact story teller (include address &/or phone number)

Location of interview (please tick <u>one</u> only) ✔	❑ Carmunnock ❑ Castlemilk ❑ Cathcart & Simshill ❑ Croftfoot ❑ Kingspark & Mount Florida ❑ Langside & Battlefield ❑ Other (please specify)
Date	
Relationship between story collector and story teller (please tick <u>one</u> only) ✔	❑ Friend or relative ❑ Co-worker or volunteer ❑ Neighbour or other local resident previously known to each other ❑ Connection through involvement in a community based organisation ❑ Other work-related connection ❑ Other non-work related connection ❑ No previous connection at all

STORY COLLECTION – INSTRUCTIONS

1.   SHOW THEM THE PROMPT CARDS AND EXPLAIN THE FOLLOWING IN YOUR OWN WORDS. These are based on previous stories that people have told us and describe how we would like things to be. Please take a few minutes to look at these prompt cards. The pick one that most resonates with you (this might because you have a similar or completely different experience). If you can think of several stories pick the one that is the "deepest", that you feel comfortable telling.

2.   NOW ASK THEM TO TELL YOU THE STORY THAT PROMPTED THEM TO PICK THAT CARD. Please tell me your story. This should take no more than 5 minutes. You don't need a long history or backstory. If you ask them to tell you the basics, you can follow up with some questions to fill in any details. At the end, you may want to check you know the basic "who, what, when?" details of the story. You may wish to paraphrase it back to them to make sure you have the story.

3.   ONCE THEY HAVE FINISHED ASK THEM TO GIVE THE STORY A TITLE.

4.   THEN ASK THE QUESTIONS ABOUT CHANGE AND RECORD THEIR ANSWERS

5.   ASK FOR ANY OTHER COMMENTS

6.   ASK THEM TO COMPLETE THE PROFILE QUESTIONS AT THE END.

7.   THANK THEM FOR THEIR HELP AND MAKE SURE THEY KNOW HOW TO CONTACT YOU IF NECESSARY.

8.   ADD ANY REFLECTIONS OF YOUR OWN

RECORD THE STORY HERE

WRITE THE STORY TITLE HERE	PROMPT CARD NO

WHAT CHANGES ARE NEEDED? Now ask them to think of **three** changes that they think would have to happen to make the best possible health and wellbeing in this area in the future.

A small change – which should be possible in the near future
For me to make
For others to make (specify who)
A modest change – which is desirable and possible but may take more time
For me to make
For others to make (specify who)
A bigger change – which is might seem like a wild dream or may take more time to see happen
For me to make
For others to make (specify who)
ANY OTHER COMMENTS?

A FEW FINAL QUESTIONS ABOUT YOU

1. Which of the following categories best describes you?

Age ✔

- ❏ Under 16
- ❏ 16 to 24
- ❏ 25 to 34
- ❏ 35 to 44

Gender ✔

- ❏ Male
- ❏ Female

- 45 to 59
- 60 to 74
- 75 plus

2. Is there anything else about you that would help people to understand your story better. Tick the ones that are relevant. For example:

- I have a disability, long-standing limiting illness or health problem
- I am a member of a minority ethnic group
- I have literacy problems
- I am gay or bisexual
- I am member of a faith group
- Something else (please specify)……..

- I live in:
  - Carmunnock
  - Castlemilk
  - Cathcart & Simshill
  - Croftfoot
  - Kingspark & Mount Florida
  - Langside & Battlefield
  - Other (please specify)

- I work or volunteer in:
  - Carmunnock
  - Castlemilk
  - Cathcart & Simshill
  - Croftfoot
  - Kingspark & Mount Florida
  - Langside & Battlefield
  - Other (please specify)

THANK YOU FOR YOUR HELP

Reflections from story collector (optional)

Annex 3 Related research of interest

Stewart W. Mercer and Graham C. M. Watt, The Inverse Care Law: Clinical Primary Care Encounters in Deprived and Affluent Areas of Scotland, Annals of Family Medicine, Vol. 5, No. 6 November/ December 2007 (quoted with permission)

Extract:

Purpose The inverse care law states that the availability of good medical care tends to vary inversely with the need for it in the population served, but there is little research on how the inverse care law actually operates.

Methods A questionnaire study was carried out on 3,044 National Health Service (NHS) patients attending 26 general practitioners (GPs); 16 in poor areas(most deprived) and 10 in affluent areas (least deprived) in the west of Scotland. Data were collected on demographic and socioeconomic factors, health variables, and a range of factors relating to quality of care.

Results Compared with patients in least deprived areas, patients in the most deprived areas had a greater number of psychological problems, more long term illness, more multi-morbidity, and more chronic health problems. Access to care generally took longer, and satisfaction with access was significantly lower in the most deprived areas. Patients in the most deprived areas had more problems to discuss (especially psychosocial), yet clinical encounter length was generally shorter. GP stress was higher and patient enablement was lower in encounters dealing with psychosocial problems in the most deprived areas. Variation in patient enablement between GPs was related to both GP empathy and severity of deprivation.

Conclusions The increased burden of ill health and multi-morbidity in poor communities results in high demands on clinical encounters in primary care. Poorer access, less time, higher GP stress, and lower patient enablement are some of the ways that the inverse care law continues to operate within the NHS and confounds attempts to narrow health inequalities.