Person Driven Care

A study of The Esther Network in Sweden and the lessons that can be applied to enable NHS Wales to become a patient-centred healthcare system

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"All too often decisions are made to 'fit' people into existing services, rather than to challenge whether the right services are available."

"There has never been a better time to move forward and show how Wales can be a leader in providing well-informed, cohesive and co-ordinated care which meets the needs of older people requiring help.

"The Esther Network has demonstrated that it is possible to devise systems and processes which align to provide patient-centred care. We have the building blocks in Wales to support an Esther network. Bodies already exist to provide information on patient values and experiences to empower staff and carers to seek support in delivering services which are most appropriate to the needs of the individual person seeking help."

Dr Bernadette Fuge, *Chair, Age Cymru*

"The Esther Network presents a simple, multi-agency approach to ensuring that the patient is really at the centre of care planning and care delivery. Asking simple questions about what's in the best interest for the person at the centre is critical for ensuring that the right decisions are made with the person concerned. All too often decisions are made to 'fit' people into existing services, rather than to challenge whether the right services are available.

"The Esther Network also provides an interesting perspective on multi-agency working. A range of people with different professional backgrounds undertake the 'Esther champion' role - a role that empowers the individuals involved to drive forward patient-focussed decision making. The integrated approach to both care planning and service delivery appears to be an important part of the success in Sweden."

Abigail Harris, *Director of Strategy and Policy,*
Department of Health, Social Services and Children, Welsh Government

"Since the event, I have been thinking about the profound effect that the story of the original Esther had on everyone present.

"It was like many of the processes that go on in healthcare. I believe we all have the patient's best interests at heart. Very few people in NHS Wales go to work without that - but then the way our organisations operate takes over and we follow the processes of healthcare that we have devised, like standard outpatient appointments. Whilst doing this, staff and patients become part of a system which has its own aims and outputs, like seeing all the patients before 5pm, giving repeat appointments when information is missing, and repeating tests that have already been done elsewhere because staff cannot access the results.

"We should be thinking about what the *patient* wants and needs from that appointment – not what the system needs and wants! Then we should design the system to deliver what the patient needs and not the other way round."

Professor Peter Barrett-Lee, *Medical Director, Velindre NHS Trust*

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Executive summary

The Welsh Government has pledged its commitment to patient-centred services, as outlined in *Together for Health*. It requires all NHS organisations and therefore all NHS staff to realign services in accordance with patient need and include citizens at the centre of healthcare planning and provision.

This white paper contains the 1000 Lives Plus recommendations for creating a person-centred healthcare system in NHS Wales. It is based on the principles that guide The Esther Network in Jönköping, Sweden, a healthcare system which is widely recognised as a world leader in patient-centred care.

There are several key areas of practice and culture where NHS Wales, and those working within it, will have to creatively seek change. The increasing pressure on the current healthcare system arising from demographic change and other external forces needs to be channelled into imaginative partnerships between healthcare systems and the citizens they exist to serve.

The following points will have a huge bearing on the ability of NHS Wales to deliver genuine person-centred, patient-centred and citizen-centred care.

- Including patients and citizens in service design and delivery is desirable and will lead to improved quality, reduced waste, better patient experience, and better use of resources.

- Patients are often best-placed to identify the things that are not working, and will often have clear and direct ideas on how to improve things.

- Becoming a patient-centred healthcare service will involve significant changes in staff attitudes, particularly the realisation that 'We all have two jobs – to do our job and to improve our job'. This will take courage, innovation, creativity and commitment.

- Leaders within NHS Wales have to see their primary role as supporting staff and giving them the 'elbow room' to get on with their two jobs.

- It follows that service improvement cannot be driven as a top-down initiative. Staff should be equipped and empowered to make changes. Bureaucracy that prevents staff from improving services needs to be stripped out.

- Concern over governance issues should not be allowed to stifle creative ideas or delay and prevent changes occurring which would result in improvements in care.

- To forge the best possible future, NHS Wales has to work in genuine partnership with the public – and this is more likely to happen in organic networks powered by passionate staff in a loose coalition of local initiatives.

- However diversity in local expressions of service should not result in variation of quality of service. Patient-centred care may look different in practice, but the underpinning theory and commitment to providing the highest possible quality in service should be present in every different flavour of healthcare.

Introduction to the contributors

This white paper is based on two presentations delivered in Wales by Nicoline Wackerberg, The Esther Network co-ordinator in Jönköping. The Esther workshop was an invitation-only introduction to the network, and the following day Nicoline presented a shorter overview at the 1000 Lives Plus National Learning Event[1].

Nicoline graduated as a physiotherapist in the Netherlands in 1982 and has subsequently worked in several European countries. She has worked in primary care, hospital care and community care services as a physiotherapist, manager and quality improvement leader. In 2001 she was named Physiotherapist of the Year by the Swedish Physiotherapy Board. Nicoline began working with The Esther Network in 1999. She currently combines her work with studying for a Masters degree in Leadership and Healthcare Improvement.

The Esther workshop also featured input from an 'Esther Coach', Kerstin Svensson, and Karen Barnett and Steven Michael from the South West Yorkshire Partnership Foundation Trust, who presented an overview of how the Esther principles have been successfully transplanted into a UK setting, as the 'Joe Programme'.

At the National Learning Event, Dr Bernadette Fuge (Chair, Age Cymru), Abigail Harris (former Corporate Director Wellbeing, Bridgend County Council) and Professor Peter Barrett-Lee (Medical Director, Velindre NHS Trust) commented on the presentation. They each contributed important considerations for all those attempting to apply The Esther Network principles to create patient-centred initiatives in NHS Wales.

An introduction to The Esther Network, Jönköping

"The Jönköping healthcare system is recognised as one of the leading healthcare providers in Sweden, which itself is regarded as one of the best national healthcare systems in the world."[2] It has a long history of involving the public in the way healthcare is planned and delivered.

The Esther Network includes healthcare workers and other carers committed to assessing their services "through patients' eyes". It started as a project in 1997, and was restructured into a network in 1999. Today the network covers a population of 110,000 inhabitants.

The over-arching vision behind the network is to ensure the elderly population feel secure and well, and enjoy an enhanced quality of life. Their slogan, "No matter where – we will be there", reflects their intention of improving services and ensuring that the elderly population in particular are able to access services conveniently and promptly, with as many health services provided as close to the patients' homes as possible.

A number of elderly people with experience of using the healthcare system have been recruited to provide their insights into how the healthcare system works. Often referred to as 'Esthers', these elderly people have proven intrinsically valuable partners in shaping

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[1] Both presentations are available online at http://www.1000livesplus.wales.nhs.uk/esther-workshop and http://www.1000livesplus.wales.nhs.uk/nle-nov-2011 respectively.
[2] Gozzard, D and Willson, A, (2011) *Quality, Development and Leadership - Lessons to learn from Jönköping*, Cardiff: 1000 Lives Plus. 4

services as Jönköping has grown into a nationally and internationally recognised leader in healthcare services.

The Esther Network has helped to focus service providers on 'patient value' – the aspects of the service that patients value most, which can be different to what clinicians and managers think is important. More efficient and improved prescription and medication routines have been designed, based on feedback from patients and staff.

Better documentation and communication of information, especially through improved IT support, has helped to improve the 'care chain'. The Esther Network has developed a 'virtual competence centre' to help transfer knowledge and competency between healthcare professionals involved.

'Esther Coaches' are healthcare workers who have been trained to enable their colleagues to focus on the patient, and to support improvements in the whole care chain to ensure systems are patient-centred. The Esther Coaches have a drive and passion for improvement work. They receive no extra payment for their involvement; it is considered part of their job, although it is a considerable extra commitment.

The Network has been supported by Göran Henriks and the Qulturum[3] in Jönköping. Esther Coaches have benefited from the quality improvement training provided by the Qulturum. Many of the Esther Network's successful ideas have been as a result of the link with Qulturum and the support it has given the network.

The Esther Network has contributed significantly to the exceptional outcomes recorded by Jönköping. This includes increased patient and staff satisfaction, greatly reduced waiting times, more effective treatment, and reduced cost.

Sweden and Wales: similarities

Sweden has the highest percentage of elderly people in its population in the Western world, and as a result its health and social care services face significant challenges.

However, the most recent demographic data for Wales indicates that the growth of the 'oldest old' in the population looks set to place great strain on the health services. Age Cymru note that Wales has the highest proportion of people of state pension age in the UK, with 25,000 citizens over the age of 90. This figure is set to double in the next twenty years[4].

As the number of 'oldest old' in the population grows, NHS Wales will need to adapt considerably. Given that Sweden is ahead of Wales in terms of this development in population demography, the success of the Esther Project is hugely relevant as the health service braces itself for the shift in need and corollary redesign of service provision that will result.

The Esther Network offers a replicable example of how to design services around the people who use them and also how to co-opt the public into the planning and provision of care. This emphasis on patient involvement is not a side-issue; it is in integral part of

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[3] The activity of the Qulturum is covered in Gozzard, D and Willson, A, (2011) *Quality, Development and Leadership - Lessons to learn from Jönköping*, Cardiff: 1000 Lives Plus.
[4] Henry, G. (2011) *'Cause for Celebration that could mean a social crisis'*, Western Mail (newspaper), Monday 29 August 2011:17

health policy. *Together for Health*, the five-year plan for NHS Wales published in November 2011, has stressed the needs for "A new partnership with the public."[5] This will be a pre-requisite of the service as it meets the challenges of the next few years.

Together for Health explicitly states that NHS Wales organisations will be expected to become more patient-focussed because "Involving communities in assessing and designing services improves those services." Similarly, "Involving individuals in treatment decisions and self-management improves outcomes." The link between improved engagement and improved health services and patient outcomes is evident and is now an intentional priority in NHS Wales.

This is "a sea-change in the relationship between the Welsh Government, the NHS and the people of Wales, based around a 'compact'."[6] As a result, "The NHS will undertake full and continuous engagement with local communities around service redesign… It will also demonstrate how in practical ways engagement is strengthening its accountability to patients and the public."

1000 Lives Plus has repeatedly emphasised the need to include patients in the design and delivery of services. The longstanding commitment to using patient stories, and the introduction of 'Stories for Improvement' in NHS boardrooms are examples of how focussing attention on the patient enables identification of problems within the system. A previous white paper warned that "organisations need to beware of 'institutional indifference'"[7] – the casual acceptance of poor care by staff who feel powerless, or are simply unequipped, to initiate changes to improve the systems that incapacitate and harm patients.

The 'sea-change' mentioned in *Together for Health* is acknowledged in 'The Projekt Esther Report'. "Moving from a functional to a process oriented healthcare organisation requires radical change in the organisation and a high level of flexibility from the personnel."[8] It requires a 'shift in attitude' among staff, towards proactive identification of issues combined with the competency to implement solutions.

In addition, a new focus on the patient involves a rethinking of role parameters, with every healthcare worker regarding 'improvement' as part of the job description. One way this has been vocalised and understood by staff is through the maxim: "We all have two jobs – to do our job, and to improve our job."

Finally, at the Esther Workshop, Nicoline explained that the project does not present 'black and white' answers to every issue. "It is not black and white. But also, even though Esther is old, it is not grey. It is very colourful." By 'colourful', Nicoline was referring to the complexity of the situation and the need for creative approaches to providing support. There are exciting opportunities ahead for those keyed up to grasp them; to successfully do so will require courage and learning – two characteristics that Nicoline described as "the key messages of Esther."

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[5] Welsh Government (2011) *Together for Health. A Five Year Vision for the NHS in Wales* Cardiff: Welsh Government. 10

[6] *Together for Health. A Five Year Vision for the NHS in Wales*. 11

[7] Aylward, M, (2011) *Are Bevan's principles still applicable in the NHS?* Cardiff: 1000 Lives Plus, page 11.

[8] The Primary Care, Department of Internal Medicine and Community Care in Höglandet and IBM Consulting Group, *'Projekt Esther'* [online] Available from http://www.lj.se/info_files/infosida31383/report.pdf (Accessed 3 Feb 2012)

Who is Esther?

'Esther' is a character created to help focus clinical and social care on the needs, expectations, preferences and anxieties of the people entering the care system. She is usually described as an older woman, living alone, with one or more chronic conditions. In practice, 'Esther' has become a generic name for any service user, although retaining the idea of an elderly person with one or more health issues.

The Esther Project's initial impetus in 1997 was provided by the real-life experiences of a patient called Esther. Nicoline retold her story[9] – she was an elderly woman living alone in a city, who woke up and experienced breathing difficulties. She phoned her daughter for help and her daughter told her to seek medical advice.

In response to her call to the local health centre, Esther was seen by a district nurse, who called an ambulance. She was admitted into emergency care where she had to retell her story to clinicians. After five and a half hours she was admitted onto a hospital ward, where she began treatment to resolve her difficulty with breathing.

At that point Esther had seen 36 different people. She had to explain her situation at almost every point in her journey – a requirement which is made much more problematic for a patient who is short of breath. Because she found the whole process confusing, and had to retell her story so many times, she was almost diagnosed with dementia by concerned healthcare staff. Nicoline concluded the story saying, "And so, we see it is the system that is making people sick."

Esther's whole journey was only launched after Esther contacted her daughter. In this instance Esther did not know what to do when faced with the onset of a new set of symptoms. Not knowing the best procedure to follow and who to call for help added to the delay in receiving treatment, and added to the workload of the primary care nurse.

Health process engineering needs to consider shortening the system to trigger the interventions that are of value to the patient sooner. This has been explored in a previous 1000 Lives Plus white paper, which concluded that 'there is a difference between getting in and getting help'[10]. Access is only part of the issue; delays inside the system account for significant wastage.

Seen through Esther's eyes there was very little value in the first five and a half hours she spent in hospital, or her interaction with the district nurse. Although staff were caring and courteous up to the point where she started receiving effective treatment, that care was ineffective in resolving her health issue.

Analysing the real-life experiences of patients helps to determine what a patient like Esther wants and expects from healthcare. This starts with receiving as much care in or near her home as possible. If hospital care is needed, she wants to return home as soon as she safely can, and have any continuing care needs in place when she gets home.

There is an important distinction here between care that is provided based on the patient's needs, and care that is provided based on the limitations of service. Healthcare

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[9] The video excerpt of Esther's story is viewable at http://www.1000livesplus.wales.nhs.uk/nle-nov11-vids
[10] Willson, A. (2011) *1000 Lives Plus and the NHS Agenda – Lessons from Systems Thinking*. Cardiff: 1000 Lives Plus. 8

that is based around patients going to the provider- for example, attending a clinic to see a specialist – is inconvenient and unhelpful for patients.

It is no coincidence that healthcare organised in this way is bedevilled by wastage in the form of missed appointments, patient non-compliance with treatment, missed diagnoses and multiple instances of 'repeat work'. It creates a culture of dependency, increasing the number of interactions between chronically ill patients and the healthcare provider, and ultimately increases the likelihood of harm caused by healthcare.

In addition to refining the system, the Esther Network also aims to improve preventative medicine and what patients can do proactively themselves. For a patient with heart failure, such as the original patient called Esther, there needs to be better information about coping with their illness.

Support and information can help reduce demands on the system – if the patient knows the right people to get in touch with and also what to do to reduce the impact of illness, then it may be possible for people to avoid emergency situations if they become ill. They will also receive more appropriate treatment, nearer to home and in less stressful circumstances than a hospital admission.

"Through patients' eyes"

The impact of the Esther Network is to reshape the thinking of healthcare providers and planners. There are three principle questions used to determine what a patient would value from a healthcare system – and answering these will enhance the patient's experience. The questions are:
- What does 'Esther' need/ want?
- What is important for 'Esther' when she gets sick?
- What is important for 'Esther' when she comes back home from the hospital?

Seeing the patient's illness as a continuum between treatment and rehabilitation leads naturally to partnership between organisations. Departments across health and social services co-operate to fulfil the patient's needs, and the relevant providers need to be working together at all stages of care to properly anticipate the next step, particularly the return home after in-patient care.

A commitment to greater co-operation between health and social services in Wales has been identified as crucial if NHS Wales is to 'break through to become world-class'. "Confusing, disconnected services fail people and do not make best use of scarce resources. The NHS must… work closely with the whole public sector to secure the best possible services and best use of available resources. Local Government is vital to health and wellbeing, through for example, its education, housing and environmental services and, of course, through social care."[11]

Assessing the care pathway (journey through the system) means actively identifying and making:
- Changes in the patient's environment, to enable them to maintain their independence.
- Changes in the way healthcare is provided.

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[11] *Together for Health. A Five Year Vision for the NHS in Wales.* 7

- Changes in methods – with an understanding of how new medicine and methods influence the process and co-operation between care-givers.
- Changes in technology, which might not be understood by the patient.

All four assessment points are made much easier by asking patients to give their opinion. Patients are best placed to know what changes will make a marked difference in their circumstances and enhance their independence. They can identify 'gaps' in the system and places where communication between care providers could be improved. Simple questions about the usability of new technology can help prevent people becoming 'cut off' from care when new mechanisms are introduced[12].

There also needs to be a strategic understanding of population changes, with healthcare systems constructed so they are adaptive and responsive as population demography evolves.

Nicoline defined the Esther Network as "A durable and energetic network … so that Esther can feel confident and independent"[13] This has an effect on both the patient, Esther, herself, and the way care is organised.

Esther:
- Knows where and who to turn to.
- Gets care in or close to her home, where possible.
- Sees primary care, secondary care and social care working in unity.
- Can access the same quality of care all over the region.

Meanwhile, the healthcare system displays the following characteristics:
- All personnel are concerned and committed.
- Staff support each other to achieve the best for the patient.
- There is a commitment to increase competence in the whole care chain.
- There is a commitment to continuous quality improvement.

The commitment to increase competency is summed up in the maxim **"We all have two jobs – to do our job, and to improve our job."** This is a central element to self-understanding for any healthcare employee in Jönköping. Accepting the status quo and passively allowing poor practice to continue is unacceptable in an organisation committed to increasing quality of both staff and system performance.

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[12] Sir Ian Carruthers has provided an example of patients being isolated by technology in Gray, J. (2010), *Accelerating best practice: Minimising waste, harm and variation.* Cardiff: 1000 Lives Plus. 10

[13] Esther Workshop presentation

Who is the patient?

Nicoline used a quote about customer service called 'Who is the customer?'[14]

> A customer is the most important visitor on our premises.
>
> He is not dependent on us.
>
> > - We are dependent on him.
>
> He is not an interruption to our work.
>
> > - He is the purpose of it.
>
> He is not an outsider in our business.
>
> > - He is part of it.
>
> We are not doing him a favour by serving him.
>
> > - He is doing us a favour by giving us an opportunity to do so.

Applying this thinking to healthcare shows how placing the patients' needs central in healthcare provision re-orders the clinician-patient relationship. The system depends on the patient because it exists to serve the patient.

Importantly, the patient is not an interruption or inconvenience to the work of clinical staff. The needs of the patient are in fact the driving force behind the employment of clinical staff – the patient is the reason we need all clinical and non-clinical staff in any given healthcare system. There is an old joke that 'Medicine would be simple if it wasn't for the patients'; however, the reality is that medicine only exists because there are patients.

Patients are not outsiders to the healthcare system. In many ways they are the only true 'insiders'. They are the ones who experience healthcare most personally – the reliability of the system and effectiveness of treatment can literally be a matter of life or death to a patient.

The patient's experience and viewpoint in the 'business' of medicine is therefore unparalleled by anyone working in healthcare. The patient ultimately is the arbiter of whether a treatment or system has worked, whether it met their expectations, and the level of quality they saw from their perspective. Gaining knowledge about the system from those travelling through it is vital to improving the system.

The attitude of clinicians that they are doing patients 'a favour' by treating them has to be challenged. It is an immense privilege to be given power over another human being and clinicians must hold that power lightly and humbly. Arrogance in healthcare staff, whether a senior clinician or a 'first-point-of-contact' administrator, impacts on the quality of care given in numerous ways, especially by excluding the views of the people with the most personal and valuable assessments of the healthcare system – the patients.

One way in which patient experience is prioritised is through introducing 'Quality time for Esther'. This is protected personal time in a social care environment such as a care home when the patient dictates what happens. It is usually a thirty minute period per week, but it enables the particular issue that concerns Esther to be resolved.

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[14] This statement has been attributed to Mahatma Gandhi, who reportedly said it in a speech in Johannesburg. It has also been attributed to the American entrepreneur L.L. Bean. The quote appears at the entrance to Bombay Hospital, attributed to Gandhi.

Networks and co-operation

The Esther Network draws its members from both health and social care services. Everyone working in the "energetic network" is expected to perform to a shared set of values and working behaviours. The networks are voluntary and organic, naturally creating a 'spider's web' of interconnected relationships.

The voluntary nature of involvement in the network underlines the 'everybody has two jobs' ethos – the 4,500 people involved 'already have jobs' as nurses, social workers, managers and so on.

Client-centeredness is the key value for all those involved in providing care. Seeing the system through the patient's eyes – and meeting their needs in the ways most valuable to them is crucial.

In organisational terms, networks do not function as a hierarchy. Although there is a co-ordinator serving the network, there is no central budget, and no bureaucracy. Co-operation cannot be enforced or controlled from above, but flows from a sense of mutual responsibility for the client.

All network members contribute to action plans, which are presented to senior executives in health and social care. Action plans are made annually, looking ahead for the next two to three years, and are reviewed regularly.

There is an annual 'mutual strategy day' which includes leaders, patients, Esther Coaches, politicians and staff. Strategy days give the network a clear vision, and naturally leads into discussion about how to make the vision happen.

Being in a network means that ideally everybody involved in the chain of care needs to consider the 'next provider'. Esther should not just be shunted into the next stage of care and regarded as 'someone else's problem now'. Hospitals should not be satisfied with providing superlative care and think 'we've done our part' if post-discharge care is less than ideal.

Every health and social care worker shares responsibility for the performance of the entire system, remembering that "The performance of the larger system can be no better than the performance of the microsystems of which it is composed."[15]

Additionally, voluntary and third sector organisations are introduced and involved early in the care system, to ensure post-clinical support from those organisations is in place as the moment Esther needs it.

Mutual co-operation sees one flaw in the care pathway as everyone's responsibility. "Your problem is my problem" is the mantra – challenges are faced and resolved together to ensure Esther does not become lost in any gaps in the system. For example, a shortage of doctors in primary care has been alleviated by a hospital freeing up some of its clinicians to work in primary care settings.

Communications between care-givers is crucial, with regular meetings between care-givers, education and understanding of the challenges different professions face in delivering services, a commitment to multi-professionalism and valuing the roles and

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[15] Joint Commission Journal on Quality and Safety (2003) *Microsystems in Health Care*

contributions of others, and a general atmosphere of openness and learning. This enables the development of a 'shared map and a shared narrative'.

Site visits between agencies and organisations are important learning opportunities.

Clinicians benefit from understanding how social workers make decisions. Similarly, social workers find it helpful to understand why clinicians place such a priority on returning a patient to their home environment as quickly as possible.

This does not always mean that individuals working within the network always work well together – the process is not "friction-free". However, disagreements are opportunities to review the network and identify the stumbling blocks that damage relationships. 'Nobody is perfect', but 'everyone is working on it'.

Networks that are "alive" (i.e. functioning well for both those who work in the network and those whom the network serves) have:
- 'Crisp' aims and priorities
- Shared optimism
- Creativity and opportunism
- Simplicity – as seen in the golden rule 'What is best for Esther?'
- A profound respect for logistics[16]

Networks also include patients. Esther Meetings are held near patients' homes and give service users opportunities to raise issues and make comments. The meetings primary purpose is to uncover 'anything we need to know about' to make the service as useful and effective as possible. These interactions are unpredictable, so there needs to be scope for reacting to issues that are raised.

Identifying needs is important, but it is equally important to know who can meet those needs. The people who can 'make it happen' are generally the people around Esther – the healthcare staff who see her regularly. Nurses are frequently the healthcare staff who have the most contact with individual patients, so it is important to ask nurses to develop solutions and test ideas.

The complexity of care requires a creative response. Compartmentalised care (with 'everything kept in boxes') will not enable a smooth flow through the system.
There is a role for senior leadership, but that role is not 'directional' but 'liberating'.

Leaders need to support the people around the patient to 'be the change they want to see in the world'[17]. Those close to patients need to take up the challenge to be the change and take the lead in bringing about improvements, and they are the best placed people to establish what constitutes a 'successful' change.

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[16] Esther Workshop presentation, citing J. McCannon & R .Perla (2009) *Learning networks for sustainable, large scale improvement*, Joint Commission on Quality and Patient Safety.
[17] This statement is adapted the well-known maxim attributed to Gandhi by his grandson Arun Gandhi

Embedding the Esther approach through the 'Esther Coach'

The development of The Esther Network, with its emphasis on meeting patient needs as locally as possible, led naturally to a new way of providing care and support: the appointment of Esther Coaches to support and inspire the staff in continuous development.

"Coaching is a way of working with people that leaves them more competent and more fulfilled so that they are more able to contribute to their organizations and find meaning in what they are doing."[18]

Esther Coaches are responsible for reminding staff to keep the patient central in the work they do. There is also an emphasis in learning from others, co-operation in multi-professional teams and incorporating a structure for improvement in the daily work.

The Esther Coaches come from a number of professional backgrounds – both clinical and managerial. They complete a short course which emphasises 'learning by doing' and includes running their own small-scale improvement project and site visits to different organisations.

An aspirational attitude is important for a coach, whose role can be defined as "Bringing a person from where he or she is to where he or she wants to go."[19] Nicoline summed this up by saying, "The power is in the room. The coach has to release that power."[20]

Esther Coaches:
- Support improvement projects in the frontline – to "Walk beside" people
- Catch improvement ideas and introduce new thinking drive for competency)
- Make the connection between daily work and improvement (the 'two jobs' approach)
- Inspire and motivate colleagues to improve (and celebrate improvements)
- Keep the focus on the patient – "Always put Esther in first place"[21]
- Introduce 'lean thinking' into everyday workflow
- Secure 'own time' for the patients, enabling the patient to set the agenda

Spurring on improvement requires a focus on solutions, rather than fixating on problems. Nicoline compared it to driving a car – the driver has the option of looking in the rear-view mirror, but most of the time will be looking forwards. There may be adverse weather, requiring the use of windscreen wipers – rain cannot be ignored, but there is no need to stop the car for it.

Coaches need to be positive – identifying the good elements even in projects that appear to be failing. There are methods to encourage positive thinking and to discover the 'treasures' in any situation. This can then lead to a balanced view of the situation and find ways to move forward.

Quality improvement is an 'opportunistic' mindset, not rigid planning that demands adherence[22]. As with most other aspects of healthcare, the improvement plans can also be

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[18] Flaherty J. (2010) *Coaching: Evoking excellence in others*. 3rd Edition. Butterworth-Heinemann.
[19] Adapted from Szabo P., Meier D. And Dierolf, K. (2009) *Coaching: Plain & Simple*. London: W.W.Norton
[20] Esther Workshop (afternoon presentation)
[21] Britt Marie Johansson, Esther Coach, quoted in the Esther Workshop
[22] See Bate, P., Mendel, P., Robert, G. (2008) *Organizing for Quality: The Improvement Journeys of Leading Hospitals in Europe and the United States*, Oxford: Radcliffe Publishing Ltd.

improved! Measuring change 'as it happens' enables quick decisions to be made and plans to evolve. Opportunities frequently present themselves, but need to be taken quickly. Empowering staff to take opportunities is an important aspect of leadership.

An 'Esther Network' in a UK setting

The 'Joe programme' in South Yorkshire has transferred the Esther paradigm into an NHS context. There are significant differences between the Swedish and English healthcare systems. For example there is more "headroom" in Jönköping for healthcare decisions to be made by the service providers, free from interference by policy-makers. This allows more scope for long-term planning and also for resources to be deployed on clinical rather than political grounds.

Joe is a 'model patient' like Esther. Instead of terms like 'patient' or 'service user', referring to Joe by name has 'personified' and changed conversations. A different persona has been developed for different services and staff are invited to identify 'their' Joe based on the people using their services.

Knowing who Joe is helps staff to understand what is important for him – his needs, the aspects of the care he receives that he considers most valuable, and what he wants from his interactions with the healthcare system.

All staff are invited to input ideas for improving Joe's experience of healthcare. Members of the public are also invited into some of these discussions and this has been useful to gain public support for certain commissioning decisions.

There is an emphasis on quality improvement and a network of quality champions has been established. This is an integral part of the long-term goal of 'partnership without walls' and ensuring a 'common approach' from all service providers.

Improving outcomes

"Find what is best for Esther and you will save money." - Nicoline Wackerberg[23]

The success of Jönköping in delivering improved patient outcomes while delivering resource savings has been covered in depth in numerous publications over several years.[24] Improving the system by reducing the number of interactions before a patient receives the health they need, and ensuring that patients do not disappear into the gaps between care services can only lead to better patient experience and clinical outcomes.

The Esther Network is a practical response to the issues that dog healthcare systems in the developed world, many of which have been very successful in combatting disease and raising life expectancy. In some ways, this has led them to become victims of their own success, as they are now called upon to care for a rapidly growing population of older, vulnerable people with several health needs.

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[23] Quote from the Esther Workshop
[24] E.g. see Baker, G.R. et al. (2008) "Jönköping County Council" in *High Performing Healthcare Systems: Delivering Quality by Design*, Longwoods Publishing. 121-144 and *'Projekt Esther'*, http://www.lj.se/info_files/infosida31383/report.pdf

There is a danger that healthcare can become impersonal, with plans being made in isolated offices, far removed from the day-to-day reality of both frontline clinical staff and the patients who often endure indignities and inconvenience in silence, rather than 'make a fuss' and risk even worse care.

The Esther Network has managed to re-personalise healthcare, and to reshape attitudes to ensure that the people being cared for are actually the primary focus of healthcare. By making every action about 'Esther' the impact of that action is transformed from an abstract idea into a concrete reality.

Even more importantly, the project has set a template for the "new partnership with the public" that the Welsh Government wishes NHS Wales to aspire toward. Any genuine partnership has to be based on mutual respect. The old paternalism – with hubris engrained in the rubric of healthcare provision and the mistaken, yet natural, belief that 'doctor knows best' – is no longer fit for purpose.

Shared decision making, successfully piloted in Wales, shows that a growing majority of patients want to play an active part in their treatment decisions[25]. This can no longer be denied to a population that is both increasingly more knowledgeable about their illnesses and available treatments, and also sceptical about the motives and abilities of healthcare staff.

Partnership working, in the Esther model, removes the latent antagonism of a clinician-patient relationship and replaces it with a collaborative viewpoint, that together the patient and the clinician are going to select and embark on the treatment path that is 'most right' for the individual's needs.

Finally, as a proactive response to the scenario that NHS Wales finds itself in, Esther offers hope that new ways of working can be fashioned that meet the hard-headed demands of economic reality without losing the ethical, caring heart that still beats within the health service. As Nicoline said, "Healthcare needs confidence – we need to feel that we can make it." Renewing healthcare by viewing it 'through patients' eyes' will help staff in NHS Wales retain (or regain) optimism for the future of NHS Wales.

Could Wales create an Esther Network?

So what should be done to introduce the Esther Network into the many different landscapes and populations of Wales? Each part of the country has different demographic issues – from congested city living, through to sparsely populated rural areas.

Genuine partnership with the public is more likely to happen in organic networks powered by passionate staff in the places where they work. These local projects could be linked in a loose coalition or collaborative, and they will probably benefit from being supported centrally. But the emphasis needs to be on central support, not central governance.

The Esther Network demonstrates that it is possible to put people at the centre when providing cohesive and co-ordinated care. All agencies need to be involved and need to understand each other's systems and processes to move towards partnership without walls.

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[25] See '*MAGIC - Shared Decision Making in the Cardiff and Vale University Health Board*', as presented by Natalie Joseph-Williams and Mike Spencer at the 1000 Lives Plus National Learning Event, 8th November 2011 http://bit.ly/magic-ppt

The starting point should always be what is best for the patient. Those working with patients need to look at the person as a whole – accounting for where they live, and their existing support networks.

Service-wide, NHS Wales need to improve at listening to people. This is more than just asking about their physical condition or illness, but asking them to relate their experience and using that information to shape services for them.

Patient-centred care means thinking differently. For example, day centres are valuable places for social contact. An elderly person who has been rehabilitated and no longer needs care at the day centre may find being 'discharged' upsetting. In Bridgend, one 89-year-old former patient now attends the day centre as a 'volunteer'.

The champions for the improvement agenda are usually on the frontline so networks need to be composed of frontline staff – the people who are in regular touch with 'Esther' and can easily find out what matters most to her.

The networks will need 'A shared map and a shared narrative' – while they will always retain their uniqueness, there must be a commonality of purpose and a common unity in their aims and methods, even if the means of achieving those aims are imaginatively different. The 'common language' of improvement introduced throughout NHS Wales by 1000 Lives Plus is one way of ensuring genuine progress[26].

Healthcare leaders' primary role will be to support staff and give them the freedom to get on with their two jobs. This means that leaders will have to let go of control. An Esther-style network is "an ecosystem, not a hierarchy". Trust is the cornerstone of co-operation and it begins with leaders trusting those they lead.

One way leaders can be of real value is to help eliminate bureaucracy that prevents staff from improving services. Leaders need to create the climate for improvement to happen and to empower people. This means changing attitudes towards 'risk' – good governance is necessary, but NHS Wales needs to mature and move away from the idea that nothing should be allowed to start until absolutely every governance issue is sorted out.

One Swedish healthcare CEO described those involved in the Esther Network as people who "dare to question today's reality and be provocative, in a constructive manner." From a patient-centred point of view, what people 'want' may be riskier than clinical pathways would usually allow. Frontline staff need to know that they are allowed – or even expected – to institute change for the patient's benefit.

Recruiting patients as 'Esthers' may prove problematic. The way healthcare is used by the general public tends to be passive rather than active. Treatment is something 'done to you', rather than an activity you participate in as an equal. Citizens need to believe that they will be listened to; that this is genuine engagement, not just a token nod to a political agenda. Creating trust between the healthcare system and the public is necessary for engagement to be effective.

Similarly, partnership within the public sector will be enhanced by greater partnership with the third sector. There are many external resources that NHS Wales could draw on.

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[26] See *The 1000 Lives Plus Quality Improvement Guide* for an introduction to the methodology employed by 1000 Lives Plus. See also *Quality, Development and Leadership - Lessons to learn from Jönköping*:7,18

For example, Age Cymru's Consultative Forum which advises the charity could also give information to NHS organisations to help with planning and provision of services.

Establishing an Esther network in Wales will take courage, innovation, creativity and commitment. It will require a change in attitude before there are changes in the ways services are provided. However, the many recent improvements in NHS Wales show that where there is a will, a way forward can be found.

Including patients and citizens in service design and delivery is desirable and will lead to improved quality, reduced waste, better patient experience, and better use of resources.

This is a difficult time and society is changing. NHS Wales can entrench services and stifle innovation, delivering fewer services in the process, or it can refresh what it is doing.

The system needs to recalibrate. Fewer people should go into hospital and the system should be in place to help them leave as quickly as possible. However, we shouldn't force people into the wrong part of the pathway, for example, moving people into care homes to free up hospital beds.

Patient driven care needs political support across the policy agenda. Simplification would help – there are many policies, targets and strategies, articulating the vision of improved healthcare in lots of different ways. It needs to be constructed in a universal way across the NHS and wider – for example, as a nation, Wales needs broader housing options. New homes being built must be adaptable to the needs of older people. There needs to be a greater range of supported accommodation. Housing policy will have a direct impact on healthcare provision and patient experience. Improvement cannot happen in isolation – although NHS Wales is a huge, multi-faceted organisation, it is perhaps not big enough to do this on its own.

The challenges for everyone working in NHS Wales are not whether they should start engaging patients, but how soon can they make it happen, and how well can they engage partners in networks 'without walls' that include relevant people from across healthcare, the wider public sector, and the nation of Wales as a whole.

Afterword

"Projects have a beginning and an end. Esther is not really a project. It is a never-ending story." – Nicoline Wackerberg

Further information

Esther website (English Language) www.lj.se/index.jsf?nodeId=31383&nodeType=12

The Esther Report (PDF) www.lj.se/info_files/infosida31383/report.pdf

Resources from the Esther Workshop are available online:
www.1000livesplus.wales.nhs.uk/esther-workshop

The 1000 Lives Plus Quality Improvement Guide, white papers and other publications referenced in this document are available online:
www.1000livesplus.wales.nhs.uk/publications

Video highlights of Nicoline Wackerberg's presentation at the 1000 Lives Plus National Learning Event can be viewed at: www.1000livesplus.wales.nhs.uk/nle-nov11-vids

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Further white papers available from 1000 Lives Plus include:

1. Accelerating best practice: Minimising waste, harm and variation
Addresses the questions: "If quality and patient safety are the priorities in an organisation, what would this look like?" and "How do we embed improvement in healthcare services?" Includes input from Professor Don Berwick, Sir Ian Carruthers and Gerry Marr.

2. 1000 Lives Plus and the NHS Agenda - Lessons from Systems Thinking
An introduction to Systems Thinking from Professor John Seddon, author of 'Systems Thinking in the Public Sector'.

3. Are Bevan's principles still applicable in the NHS?
A study of the NHS in Scotland, England and Wales looking at how well each service reflects the ideals of the founder of the NHS, Aneurin Bevan

4. Quality, Development and Leadership - Lessons to learn from Jonkoping
An introduction to the approach of delivering health services by Jönköping County Council in Sweden, and what can be learnt and applied to Welsh healthcare.

5. Is healthcare getting safer?
What has been the result of over a decade of national and international work to improve safety in healthcare? Professor Charles Vincent attempts to answer this crucial question.

6. Attaining Peak Performance
Canadian and NASA astronaut Dr Dave Williams addresses issues of working safely and effectively in high-risk operational environments, including a look at achieving excellent team and personal performance.

To access any of these papers, please visit www.1000livesplus.wales.nhs.uk/publications

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About the author

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Qualifying as a dietitian in 1983 and after specialising in paediatrics, she became Chief Dietitian and then Head of Therapy Services at North Glamorgan NHS Trust. This was followed by a period managing mental health services. In 1998 she took up the role of Assistant Director of Clinical Development to lead the strategic implementation of clinical governance across the Trust.

She joined the Welsh Government in 2001, initially as project manager for patient safety and developing the Welsh links with the National Patient Safety Agency.

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