The Healing Shift Enquiry

creating a shift in health care

Annual Report January 2013

The Healing Shift Enquiry addresses the impasse of today's health care model in the face of the long-term conditions epidemics by seeking an emergent perspective from the study of the enhancement of *individual* healing change, and asking how this can be enabled, learned, and scaled up to wider levels of change.

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Preface

This annual report is offered by the project team to summarise the work to date of a remarkably positive collective endeavor that we share with many patients, care staff, and creative partners. At its core this work acknowledges that the current ways of approaching health and wellbeing are falling short of what is needed and possible when facing the chronic diseases and distress common for so many of us in modern life. It presents inspiring progress that many people are making in finding better ways of caring for themselves and others, when they explore navigating health challenges with a fresh map – one that is predicated more on our capacity to care than on our technology, and one that more aims to enable our strengths than fix our brokenness. That may sound theoretical, but this report shares how it is being successfully explored in a practical way, modeled in the challenging world of today's health-care.

Director. 16th February 2013 www.david.reilly@mac.com

This Enquiry is working with its sister project:
The Cultural Influences on Well-being in Scotland/ Afternow.co.uk
The Department of Public Health, The University of Glasgow.

and in partnership with:
The Adhom Academic Department & Adhominem Charity;
Clinical Priorities Team, CNOPPP –Chief Nursing Officer,
The Scottish Government; NHS Education Scotland;
The Department of Public Health, NHSGG&C;
The NHS Centre for Integrative Care;
Nairn Healthcare Group; NHS Highland;
The Department of Palliative Care, NHS Forth Valley.
NHS Highland R&D Institute.

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Chapter 1. Summary Reflections

Background
The Healing Shift Enquiry centres in the study of people's innate capacity for creative change, healing, recovery and wellbeing. From there it explores scaling up this knowledge to create fresh approaches to health and wellbeing, through the expanding layers of self-care, and health care and its environments, staff development and welfare. It then considers wider systems and policies and cultures, working with its sister AfterNow.co.uk project.

Aims & Questions
In a context of human caring and health care services, the practical focus of this enquiry is on finding better ways to support the enablement of a healing response in people; what they can do for themselves to feel better, get well and stay that way, and what helps people cope and thrive, especially in the face of long-term conditions. This orientation towards unlocking positive potential differs from, but complements, disease focussed care.

These practical aims are informed not by a theoretical model or policy, but from the enquiry's generative detailed study over years of what it has called the 'healing shift' – people's experience of a successful transformation in their wellbeing and health - in this case triggered by one-to-one health care consultations that did not lead to drugs or others external interventions, but rather consciously aimed to be therapeutic in their own right rather than just practical transactions. This study has used deep listening and co-enquiry to try and find better answers to questions such as: *What is healing? How can healing be enabled? How can people better learn to enhance their own wellbeing?* and *How can practitioners learn to support people with this?*

Developments
This has led to new service development models, new designs. What would services look like if they held individual's inner capacity and its enablement as central? These have placed fundamental importance on supporting the conditions for getting better one-to-one work, and from there the enquiry has explored scaling the knowledge gained up to group-based programmes (like the WEL programmes for patient care and staff welfare); staff training in therapeutic encounter; contributing to integrative care service redesign; policy discussion, particularly in the realm of long term conditions; consideration of health care environment designs, and wider civic conversation and public health concerns. These have seeded service developments in a number of Health Board areas in Scotland, and contributed to education and discussion wider afield in the UK, USA, Europe and Japan.

Results & Evaluation
The work grows through cycles of learning and formal evaluation. The current evaluation report up to 2012 suggests we are on solid ground, with good evidence emerging that rooting service design and wellness courses in the study of healing change process appears to yield helpful results, for patients and staff, creating more satisfying, successful and efficient ways of care. There is important potential for scaling this approach up to think in fresh ways and create cultural shifts to assist the current impasse in our models of care in long-term conditions.

Vignettes of Results

Studying Therapeutic Encounters: a summary from one of the enquiry's earlier small case series suggested that initially all participants felt stuck in their situation of being ill, due to distress or fear and their dependency on medicine. A transformation only took place when the participants felt relaxed, found hope, could understand their situation, and saw new possibilities. When these factors had taken a strong hold within the person, they developed a sense of responsibility, learnt to cope, felt more confident and could rely on their own strengths, reducing their dependency on medicine.

Teaching Therapeutic Encounter - Training for Staff

- Having completed Part 1 two and a half years ago, several of its contents have remained with me.
- A rare opportunity to bring core values of caring profession into focus
- Excellent, thought provoking day which has stimulated me to be more conscious of my interviews with people
- Really enjoyed and feel I got a lot out of course, will change the way I interact with people and treat myself
- Excellent combination of practical points and backing up by evidence

TheWEL Course feedback is consistently and overwhelmingly positive. For example - the patient WEL course in November 2012 received a rating of Excellent from 54% and Outstanding from 46% and comments like:

- *You have given me such a wealth of advice to follow but helped me realise it's up to me to alter so many of my past thoughts and reservations about myself.*
- *Absolutely loved it.*
- *All the information came to life.*
- *A further building block for me.*
- *It's amazing how once broken into pieces and explained so well that I find hope to help myself cope better with my future worries.*
- *Found this very difficult (in a good way) as I have always resisted facing up to the fact that issues are internal.*

The StaffWEL

By end of 2012, 80 of the 280 staff in a health centre in Nairn in the Scottish Highlands have attended a StaffWEL course, identical to those offered to their patients. Their concerning initial levels of distress, loss of wellbeing, and adverse shifts in biological markers, are on par with the first 80 patients. Like the patients, staff gave very high course ratings, and reported significant positive shifts in wellbeing, and self-care behaviours. The staff self-generated waiting lists for further courses, and by the third intake, 13 of 20 prospective participants reported making positive changes already, influenced by previously attending colleagues – suggesting a successful seeding of cultural shift.

Public Health: Extracts from the Report of an External Visiting Team's Evaluation Learning Journey

Cultural Influences on Well-being project team, www.afternow.co.uk. Nairn January 2012

… it became clear that we were witnessing evidence of a remarkable qualitative change in participants' capacity for self-care, resilience and wellbeing – staff and patients alike... Staff had developed greater understanding of and empathy for their patients, and understood the importance of self-work, whilst their patients now understood the healthcare relationship as a joint enterprise, with shared responsibility. The sense of energy and purpose, enthusiasm and renewed meaning in life and work generated by participation in this programme was readily apparent to the observing group. …manifest in patients' new acceptance of their condition and their responsibility for purposeful work on their own health and wellbeing… unexpected positive effects on family life, not least in terms of healthy eating and improved family relationships. Effects also extended into the working lives of staff participants, where 'care' had a new, deeper meaning. The 'healing shift' appears to be embodied and lived, rather than simply a cognitive change. Participants at all levels were eager to see this approach transferred to the broader community, and other service sectors.

We are convinced that the implications of this approach for public health policy, and for the future of the NHS in Scotland, now deserve the most careful consideration.

Chapter 2. Introduction To The Report

This Annual Report describes the Healing Shift Enquiry developmental project and programmes – including TheHEAL, TheWEL, StaffWEL and Therapeutic Encounter Training – and the progress made so far up to the end of 2012.

More specifically, this report offers:

- A brief description of the background to the Healing Shift Enquiry, its current projects, and the partners involved.
- An interim report of the current developments, and the potential growth and likely flow of the work.
- A summary of the formative progress made in the ***Phase I*** Evaluation (2007-2009).
- Results to date of the on-going ***Phase II*** evaluation (2011-2015) up to the end of 2012 and a programme of the on-going evaluation elements and streams of enquiry.

Chapter 3. The Healing Shift: The Core Enquiry and The Five Layers

The Healing Shift Project has grown from a 25 year enquiry into creating better care by using a healing-centred and integrative approach to change, recovery and wellbeing - a vision later characterised as *The Fifth Wave of Public Health* [1]. To date the work has developed a focus on enhancing consultations and therapeutic encounters and linked practitioner training programmes, new models of clinical care, staff wellbeing programmes, patient recorded outcomes, health care environment designs, and wider developments of new ways of looking at health and care. The outcomes for patients and staff have been enhanced.

In contrast with external interventions, this project centres on a **core enquiry** into people's own capacity for healing change, and how it might be enhanced, sometimes in recovery, but always in wellbeing. From there, the enquiry explores how this understanding can be scaled-up to inform **five surrounding layers**: firstly, the self-care relationship; secondly the one-to-one healing encounter – considering both the patient and the practitioner's journeys. From this healing triad of core enquiry, self-care and one-to-one (coded below as The HEAL Project), the work explores scaling-up in the third layer to groups of people (The WEL Projects) and in the fourth layer towards the wider system and policy, and finally, the fifth layer considers its potential to help inform cultural change and environmental issues.

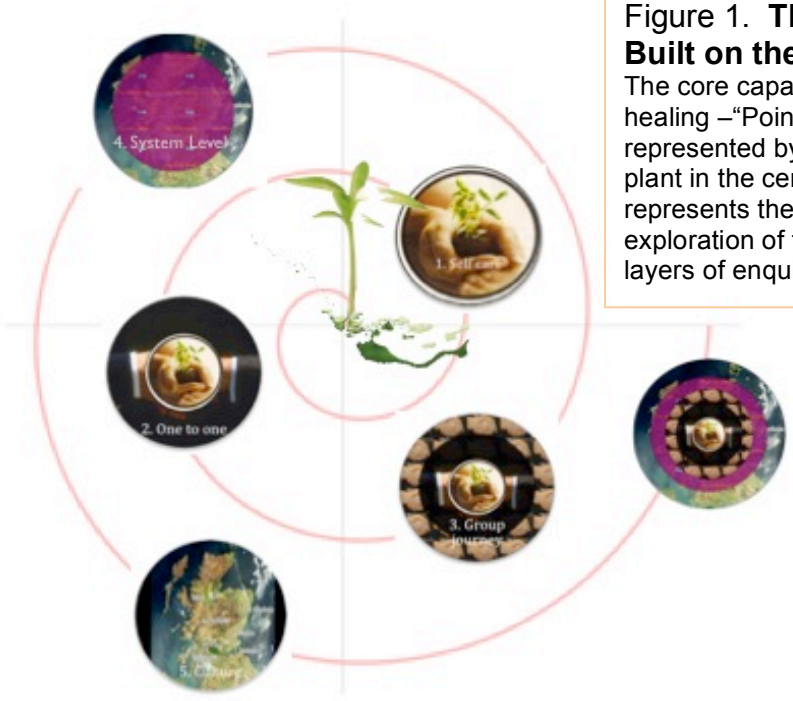


Figure 1. **The Five Layers Built on the Core Enquiry**. The core capacity for change and healing –"Point Zero" is represented by the germinating plant in the centre, and the spiral represents the scaling up exploration of the learning to 5 layers of enquiry and development.

[1] The Fifth Wave - Searching For Health In Scotland, Compiled by Andrew Lyon,. (2003). Scottish Council Foundation. See also www.afternow.co.uk for linked Public Health discussion

[2] Hasegawa, H , D Reilly, S Mercer, and A. P. Bikke. "Holism in Primary Care: The Views of

3.0 Point Zero -The Core Enquiry

This takes the phenomenon of healing change in people as the start point and reference point for in-depth learning and development. The focus is on understanding the healing change capacity and process within an individual. The work studies the process and results from therapeutic encounters, and links this to other sources of understanding. What is it and how can this be enhanced across the spectrum of what can be cured and what cannot? What if self-healing change was used as the basis for designing health care? How can this knowledge guide the five layers of the enquiry?

3.1 Layer 1 - Self-care.

The Self-care Journey is the key to sustained support for the self-healing capacity. It is determined by the self-relationship. How can the self-relationship grow in ways that support sustained improvement in self-care? One hypothesis is that self-compassion may be of vital importance. How can health care work catalyse and support self-care?

3.2 Layer 2 - One-To One Meetings: Therapeutic Encounter

The therapeutic encounter has two key fields of study in the project:

- **The Individual's Healing Journey.** How can a person's healing responses, and self-care, be affected by their one-to-one healing encounters, relationships and Therapeutic Journey? How can this be improved and measured? Support for the person's "inner journey" complements the current dialogue on improving the outer journey through the care system: for example, the NHS Quality Strategy; the Person-centred Care Strategy; Caring for the Carers; the Spiritual Care Policy; the ALLIANCE work; the Self management Programme and the Caring Behaviours Assurance work.

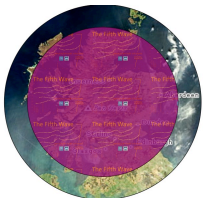
- **The Practitioner's Journey.** How can practitioners be supported to place greater emphasis on relationship and enhancing healing change? The project is developing and evaluating models of practitioner development and educational work – Therapeutic Encounter Training (some courses have been linked with NHS Education Scotland). It synthesises and applies findings from the other layers and recognises practitioner stress and the constraints of time and system design that are limiting development.

Point Zero and Layers One and Two are collectively coded as The HEAL Project.

3.3 Layer 3 - TheWEL Project: The Group Journey

This project asks if the core principles of human healing, self-care and therapeutic encounter can be scaled up to group work. ***Phase I*** is now complete, and from it came The Wellness Enhancement Learning Project (WEL) and its evaluation working with people with a diagnosis of CFS-ME. This work is now being developed further through the implementation of ***Phase II*** and has expanded to the GeneralWEL, PrimaryWEL and StaffWEL programmes. A pilot of a SelfWEL programme is now being planned – to see what can be done with the WEL approach and materials for those unable to join the group programmes.

Point Zero and Layers One, Two and Three are referred to collectively as The HEALWEL.



3.4 Layer 4 – The System's Journey

This project aims to explore the scaling up of the healing principles to the level of professional practice and system design. The project's earlier National GP Survey highlighted that holism is under strain[2]. The work to date has already made many contributions to a wide range of dialogues, conferences, and national policy development in linked areas, and it is expected that this will grow.

3.5 Layer 5 – The Cultural Journey

The links between the concepts underpinning the Healing Shift Enquiry and new approaches in Public Health were first explored in the earlier 'Fifth Wave' report from the Public Health Institute of Scotland. This grew into a direct cross-linkage to the sister project *The Cultural Influences on Wellbeing in Scotland* led by the Department of Public Health, Glasgow University, and funded by the Scottish Government's Health & Social Care Directorates. Multiple works have been published to support wider debate. http://www.wellscotland.info/publications/consultations4.html and www.afternow.co.uk.

An earlier phase of the project helped raise awareness and standard in the design of hospital and care physical environments by leading a development to build a new hospital that modelled the creating of a healing environment. Among other innovations, this pioneered the use of a lead artist – Jane Kelly – integrated within a design team. (See the Healing Space section on www.thehealingshift.org). The result has won a number of awards, and influenced practice in health care design.

[2] Hasegawa, H , D Reilly, S Mercer, and A. P. Bikke. "Holism in Primary Care: The Views of Scotland's General Practitioners." Primary Health Care Research and Development 6, no. 4 (2005): 320-28.

Chapter 4. The Partners

Based on the project's previous achievements in creating new models of care for people with long term conditions, in 2005 the Department of Public Health in NHSGG&C commissioned the project Director to create a new service for people with CFS/ME (Chronic Fatigue Syndrome/ Myalgic Encephalitis). The challenge was addressed by piloting a development and evaluation of a group-based Wellness Enhancement Learning Programme – TheWEL. Good results as judged by service and research evaluation* (results on www.thewel.org), led to the programme being adopted as a standard NHS service in NHSGG&C from 2008. This work is referenced in the Good Practice Statement on ME-CFS published by the Scottish Government in 2010. The development was then expanded into a general version (GenWEL), and by 2012 over 1000 people had entered the programme.

In 2004, the Minister of Health expressed the view that he would wish to see the integrative ethos, which this work has been pioneering, disseminated through the NHS. In 2008, with the backing of the CMO and Deputy CMO, a partnership began with the Clinical Priorities Team of the Government's Health and Social Care Directories. This created further shared projects developing integrative approaches that helped inform the development of the national Long Term Condition Strategy, later joined by the Chief Nursing Officer, Patients, Public and Health Professions (CNOPPP) in 2011.

The project is grounded in what recent discourse might call an asset-based approach, and continues to support the move towards a more person-centred and enabling, self-management approach with people in health services. Recognising the need to also support NHS staff, and in alignment with a positive staff governance approach, a StaffWEL version for professional healthcare staff began in 2010 with The Department of Palliative Care in NHS Forth Valley. In 2011, an expanded StaffWEL and a PrimaryWEL were launched in partnership with Nairn Healthcare Group, Nairn Town And County Hospital and Primary Care Centre with WEL Co-Director Dr Audrey Banks.

The current ***Phase II*** development and evaluation cycles build on the previous work with a since-evolved model, in expanded contexts, with increased numbers and further quantitative and in-depth qualitative evaluation using patient-centred approaches. Chapter 7 contains a fuller description of the HEALWEL Evaluation Plan and methodology.

The Healing Shift Enquiry work is moving forward as a partnership between:

- The Adhom Academic Department & Adhominem Charity that runs the project, supplies infrastructure and has committed its existing funds to this work.
- The Clinical Priorities Team, and CNOPPP– Chief Nursing Officer of the Scottish Government, which offer support for the current project development.
- The NHS Centre for Integrative Care, Glasgow - with part contribution to the Director's non-clinical work (an endowment ending in March 2013), and serves as one of the clinical centres of the patient WEL evaluation.
- The Department of Public Health in NHSGGC– which funds one of the post-doc researcher posts.

- Nairn Health Group, Nairn Town And County Hospital & Primary Care Centre, acting as clinical and education centre and offering infrastructure support, which the project funds must cover.
- The Department of Palliative Care in Forth Valley – which has acted as a clinical and education centre.
- NHS Highland R&D Institute – is supporting some project time for the Nairn GP Co-Director.
- A number of partners in education and development work, including Ewan Kelly of NHS Education for Scotland, and Dr Erna Haraldsdottir of Strathcarron Hospice.
- Dr Andrew Lyon of the International Futures Forum - creative input to the project development, and guiding the Civic Conversation initiative in Nairn.
- The Afternow Team of the University of Glasgow led by Professor Phil Hanlon – working as a linked sister enquiry, and acting as an external advisory board.

The support of the above partners joins with the Research Team, which includes post-doc researcher Dr Patrick Quinn, Research Assistant Fiona Smith, Public Health Programme Adviser and Honorary Research Fellow Cath Krawczyk, and Honorary Clinical Research Fellows Dr Audrey Banks and Professor Charles Clark, working with a clinical team for the WEL and sister teams in Glasgow delivering other group based courses.

The Principle Investigator, and Director of The Healing Shift Enquiry and TheWEL programmes is Dr David Reilly - National Clinical Lead for Integrative Care 2008-11; Consultant Physician The NHS Centre for Integrative Care; Honorary Senior Lecturer in Medicine, The University of Glasgow; Visiting Professor, the Center for Integrative Medicine, the University of Maryland School of Medicine, USA.

The delivery of the work to date, backed by the ***Phase I*** and emerging ***Phase II*** results, have thus far provided evidence to justify the establishment of an on-going NHS service in Glasgow, and on-going investment in the work and the main study.

The next Chapters will give more detail on the project streams; summarise the results of the previous ***Phase I*** Evaluation work; then outline the current ***Phase II*** enquiry; and finally give a summary of the results to date from that ***Phase II***.

Chapter 5. Summary of The HEALWEL Projects & Enquiry Streams

In subsequent sections of this report we will describe recent progress and developments of the projects, followed by the evaluation models, and results to date. Firstly, in this section we will describe the main project development and enquiry streams and using the five layers, previously described, We will focus mainly on Point Zero and Layers One, Two and Three - activity coded as TheHEAL & TheWEL developments.

5.1 TheHEAL Projects

5.1.1 The Core Enquiry: Point Zero, The Healing Shift & The Layers of Self-Care and One-to-One Encounters

At the centre of this enquiry lie questions such as *What is healing? How can healing be enabled? How can people better learn to enhance their own wellbeing? and How can practitioners learn to support people with this?*

The project combines an examination and distillation of existing research and knowledge on the healing process. It then aims to add to this through fresh enquiry and new learning with patients, practitioners and course participants engaged with the project. This draws on many years of formative clinical therapeutic encounter development, plus the ***Phase I*** Evaluation (2007-2009) pilot work that studied people's experience of undergoing helpful shifts and transformations in their wellbeing as a result of one-to-one medical consultations. ***Phase I*** used qualitative analysis of recorded consultations, and subsequent interviews with patients, to sketch initial learning and themes and to consider apt methods of enquiry. A summary from a small case series [3] suggested that initially all participants felt stuck in their situation of being ill, due to distress or fear and their dependency on medicine. A transformation only took place when the participants felt relaxed, found hope, could understand their situation, and saw new possibilities. When these factors had taken a strong hold within the person, they developed a sense of responsibility, learnt to cope, felt more confident and could rely on their own strengths to reduce their dependency on medicine. These findings will be expanded in ***Phase II***.

[3] An exploration of the phenomenon of healing through interpretative phenomenological analysis. Annemieke P Bikker, David Reilly

5.1.2 Therapeutic Encounter Training

The Therapeutic Encounter course has been developed over the last decade. These workshops aim to support professionals, of any discipline, in their efforts to improve, even transform the quality and effectiveness of their encounters and relationships with their patients or clients. New knowledge, and examples of successful practice are used to help them consider how to make the meeting therapeutic in its own right, helping achieve an activation of the patient's own capacities for recovery, coping, wellbeing and self-care. This involves supporting what might be called The Practitioner's Shift – moving their core purpose towards wellness enhancing partnerships with patients.

To date it has developed as a stand-alone 1-day course, with the option of a Part 2. This has been run in a number of UK sites, principally in Scotland in Glasgow, Forth Valley, Highland and Grampian Health Boards, and overseas principally in the USA, Japan and Canada. So far in the ***Phase II*** evaluation it is being delivered in NHS Forth Valley and NHS Highland regions, and in the latter is being experimentally combined with a preceding StaffWEL (to be described below). This combination takes a practitioner through an experience of addressing their own self-care and change process, and then in the second course asking how that learning can be blended with their clinical practice. Consideration is being given to subsequent support and the building of a Community of Practice.

5.2 TheWEL Programmes: Scaling-up TheHEAL Learning To Groups

5.2.1 The Core WEL Programme

The WEL Model aims to support the movement from a medical model of patient care to one of self-enablement and wellness enhancement. It began with a question: *Could the learning born of the study from creating enabling therapeutic encounter be scaled into a group situation?* In 2004 this was first tested as an action research developmental-demonstration model in The NHS Centre for Integrative Care in Glasgow. This was in partnership with NHS Greater Glasgow and Clyde (NHSGGC) Department of Public Health who commissioned the project to innovate a service for people with CFS/ME.

The WEL has now grown from the early CFS/ME version to the main General WEL version that seeks to help people with any long-term condition. For example, for the PrimaryWEL intake in Nairn (more on this below), most of the first 20 participants had more than one issue and typically 3 to 5 long term conditions. More specifically, 9 had chronic pain, 17 had chronic depression/anxiety, 9 had CFS/ME and 3 had diabetes. It's worth noting that if a diagnosis-focused approach was taken, most would need to attend multiple programmes. The Nairn referral guidelines for GPs is given in Appendix 1.

In contrast to external interventions, TheWEL model centres on a core enquiry into people's own capacity for healing change, and how it might be enhanced, sometimes in recovery, but always in wellbeing. The core aim is to trigger a self-sustaining activation of better self-care and wellbeing. It encourages people to support their inner capacity for resilience, recovery and healing. It is about change and the change journey. This shift is then modelled and supported with examples of self-care approaches including cognitive skills, mindfulness, meditation, and practical everyday ways of living – such as what people are choosing to eat.
The participant introductory leaflet (Appendix 2) explains that: "*Many of us face real challenges with our health or wellbeing. If you then add a long-term condition or stress you end up with a loss of peace, facing symptoms, loss of function and quality of life, and maybe problems like feelings of hopelessness, isolation or loss of self-esteem. The WEL is a holistic programme that aims to help you*:

- Develop a deeper understanding of your challenges and so achieve better self management
- Develop skills in creating the best conditions for strengthening your self-healing
- Increase your wellness and strengthen your on-going commitment to self-care.

All participants at all sites attend this core WEL programme for 16 hours over four half days at around weekly intervals, backed up with the home resource pack of a manual and a set of DVDs. The course is delivered by senior clinicians, who have substantial experience in working in a WEL-type way, in both one-on-one practice and groups. The primary purpose is to 'seed' ideas and practices aimed at fostering

intentions towards self-care, self-compassion and ultimately, healing change. The therapeutic environment is consciously designed to be a welcoming space, which is 'alive' and where participants can feel safe to express themselves in their own ways. The aim here is to model 'patient-centred' care. While substantive areas like advice on nutrition and stress management, meditation, cognition and mindfulness are engaged, the underlying emphasis is to focus on the person's strength and capacity for achieving sustaining self-care and wellness enhancement – as a basis for transformation and personal growth.

During this period participants are encouraged and supported to reflect on their journey thus far, to consider the conditions and life that may have led up to their illness and, through self-compassion, improved self-care and stress reduction, to begin their healing journey. Specific skills introduced in the Foundations part of the course include the meditative practice 'Heartmath', an evidence-based technique aimed at promoting 'cardiac coherence' which is defined as the coupling and synchronisation of the rhythm of breathing to the rhythm of the heart. This state of coherence is associated with a general sense of wellness and health benefits across a number of areas. The Foundations part of the course provides a bridge to other modules that might follow.

Each WEL study cohort has around 20 men and women over the age of 18 drawn from the following:

- A confirmed diagnosis of ME/CFS – a Glasgow only option

- A range of general medical diagnoses and healthcare problems and conditions

- The StaffWEL version has diverse groups of frontline NHS staff (e.g. nurses, doctors, physiotherapists, receptionists etc.)

5.2.2 TheWEL Course Options

The course options vary in the study locations in a way that allows useful comparisons and comments on what can be achieved with a more minimal input:

1. **All participants** at all sites attend **the core WEL programme.**
2. **Glasgow Participants** continue from the core programme into a 3 week additional course ***Moving Into Balance.*** This complementary course is directed and delivered by Stephanie Wilson a Senior Physiotherapist. It brings further ideas and practices in self-care including developing key areas - such as improving sleep, pacing our physical energies and rhythms, exercise, posture and yoga practices - www.movingintobalance.co.uk .
3. Glasgow Participants have an optional supplement of ***MBCT: Mindfulness Based Cognitive Therapy*** delivered by senior clinicians in eight 2 hour sessions. Around seventy percent of people attending the core WEL programme opt for MBCT, and this is timed some months after their initial programmes to allow a period of consolidation of the earlier WEL learning and practices. MBCT increases self-awareness and self-acceptance, reducing reactivity to passing thoughts and emotions and improving the ability to make adaptive choices. It is expected therefore to be synergistic with the core WEL course - see Appendix 2 and 3 for a participants' information leaflet and an

overview of the course.

4. **All Highland based, Nairn participants** do not attend the Glasgow-only options 2 or 3 above. In the Nairn PrimaryWEL and StaffWEL development version (described below) the only follow up after their 4 week core programme is a half-day meeting at around week 10 – currently referred to as ***Part X***.
5. In 2012, a pilot group of participants in Highland were offered a developmental version of an **MBWEL: Mindfulness Based Wellness Enhancement**. This course was facilitated by Drs Susan Brown and Jenny Nicol, with WEL co-director Dr Audrey Banks, all being teachers who had undergone a WEL journey and were previously trained as MBCT or MBSR teachers (MBSR is Mindfulness Based Stress Reduction, the model that seeded MBCT). It was designed to directly continue the WEL journey, interleave and re-enforce the learning from it, and add additional learning and practice in mindfulness.

To date, Forth Valley participants have had only the core WEL programme.

5.2.3 PrimaryWEL & StaffWEL Versions

The original WEL development was developed within a secondary/tertiary care setting. A PrimaryWEL version for General Practice was launched in Nairn in September 2011 in partnership with Nairn Healthcare Group and Nairn Town and County Hospital and Primary Care Centre, co-directed with Dr Audrey Banks.

However before The PrimaryWEL launch it was decided to begin with a version for the centre's staff. A first StaffWEL had already been piloted with Palliative Care nurses in Forth Valley in 2010 in partnership with Sandra Campbell, Nurse Consultant. Analysis of the findings from this successful pilot suggested that running a StaffWEL ahead of the patients WEL programme in Nairn might enhance the effectiveness of the overall approach by seeding a supportive culture for a subsequent patient programme. This view informed the planning of a WEL approach for Primary Care in Nairn with the support of funding from NHS Highland.

The Nairn StaffWEL began recruitment in May 2011. There were two main aims: to create experiential learning for the staff of how to help patients make the shift towards sustainable self-care and wellness enhancement learning, and secondly, the equally important aim to help staff achieve this for themselves, and so support and help them in addressing their own stress, wellbeing and self-care.

The impression gained is that many staff need the WEL programme as much as, sometimes more than, the patient groups. The programme has been enthusiastically taken up, and some example feedback and evaluation results will be given later.

Chapter 6. Project Developments

Funding from Scottish Government and other partners for 2012 secured the continuation and development of the main clinical programmes that underpin the work. In turn these learning and action research cycles have allowed continued growth and re-design of the core programmes. We have been able to seed wider dissemination of the underlying principles and learning into wider community discussion. In turn, these developments have allowed continuation of the ***Phase II*** evaluation, which we will summarise in a later section. Our partnership base has continued to grow, with joint initiatives with NES colleagues, and support from NHS Highland R&D Institute.

Example Developments of the HEALWEL Programmes

6.1 The Core HEAL Enquiry Work

This has continued in 2012, expanded into a formal literature review, and a few remarks will be made about this in the Evaluation section that follows.

6.2 The Therapeutic Encounter Course

- The training continued in Forth Valley, including a Part 2 follow-up programme. With colleagues in Forth Valley and NES, plans were raised for a 2013 development day on fostering Person Centred Care and building Community of Practice.
- We ran a first exploratory pilot of some Forth Valley nurses doing the Therapeutic Encounter course together without an external teacher, using the course on video, backed by the manual. Their feedback was good, and they seemed well able to then join in on the Part 2 training day, suggesting possible benefits in the self-led training model.

- This lends encouragement to our work of the generation of a "**teachers manual"** – an in-house code for the work of distilling and disseminating the core principles of wellness enhancement, sustained enablement of self-care, and therapeutic encounter. We will explore if this can be based on video editing of live teaching, and clinical work. Partners will be sought to further develop this element in 2013.

6.3 WEL Course Models

- Recruitment into **TheWEL and PrimaryWEL** versions continued throughout the year allowing around 160 more people to benefit. Project work allowed on-going upgrading of course support materials.

- **The StaffWEL** programme in Highland was able to be continued. The first course had such a positive impact it generated a waiting list for a second course before it was even finished. That pattern has continued and a fifth intake is planned for February 2013. The Nurse Manager for Nairn Hospital set a goal to have all 40 staff trained in this programme saying this is the most effective programme she has ever experienced. Some examples of participant feedback are given in the evaluation section, as well as evidence that a cultural shift seems to have been seeded in the staff community.

- As described in 5.1.2 above, a pilot is planned of running a cohort who have completed a StaffWEL who then go on into a Therapeutic Encounter day.

- Early work has begun considering the feasibility of a **SelfWEL approach** – using WEL materials in self-led home learning for those who cannot attend groups. There is an emerging literature in this area suggesting benefits to such an approach.

- **MBWEL** Mindfulness Based Wellness Enhancement.
  In ***Phase I*** of the development in Glasgow, the project seeded the first trainers' course in Scotland of MBCT (Mindfulness Based Cognitive Therapy) in partnership with The University of Bangor. As described above in the WEL Course Options section, we were able to pilot a new design of Mindfulness Training more directly linked to the WEL.

- We have been collecting feedback from **diabetic patients** who have been on TheWEL. They welcomed our idea of considering a WELDiabetes supplement specifically tuned for them, but they emphasised the value of adding that to the core generic group rather than having a diabetic only group. We will build on this to explore how the potential of TheWEL approach with diabetic patients might contribute to primary care input in Nairn, to diabetic Managed Clinical Networks and the Scottish Diabetes Group. We believe there is real potential for these developments to make a significant contribution to the Government's Diabetes Action Plan and the huge challenge posed by diabetes in Scotland

- There is also the larger-scale issue of **pre-diabetes** and the impending expansion of the diabetes epidemic, with its link to other conditions like cardiovascular disease. Our initial biometric results (more on this in the results section) suggest markers for metabolic syndrome and pre-diabetes which are concerningly high in our patient and staff participants. These are unexpected important findings. Coupled with our evaluation results, which suggest potentially important helpful changes in people's diet after TheWEL, we believe this merits further exploration as the project develops. Given that metabolic syndrome is primarily characterised by abdominal obesity, this approach could contribute to Scotland's 2010 Obesity Strategy.

  When our data is sufficiently developed in the course of 2013, we will hope to arrange contact and exchange with key players in this area – such as the Scottish Government's Lead Clinicians in the field like Dr Johnny McKnight. We also consider that conversation with national leads within the Person-Centred Care Strategy and the Caring Behaviours Assurance work would be helpful.

6.4 Participant Led Initiatives

Some tentative experiments created by participants included: in December 2011, WEL participants seeded a community based peer-led WELJourney support group, this had initial success, but is judged to need a change of format; In June 2012 some participants explored a paired-Buddy system; some staff organised meetings have

taken place; and some experiments in using social media are being tried. Participants have reported showing course DVDs to family members and friends, shared the manual and web links, and in one case showing a course video in the community to groups of pregnant women. All these are in the early stages of experimental development and will need support as the project develops. It's worth noting that it was a spark from Kate Clark, a StaffWEL participant that seeded the idea of the Civic Converation, when after her course she asked *"How can we bring the Fifth Wave to Nairn?"*

6.5 Dissemination, Community Reach & The Civic Conversation

The project continues to contribute widely to dialogue and development through contributions to conferences, teaching events and collegiate discussions. Below are some of the ways that the Nairn based work has been and will also explore other forms of community involvement and linkage.

6.5.1 The LEARNS

In September 2012 around 100 NHS staff, academics, therapists and previous WEL participants took part in a LEARN meeting around TheWEL and StaffWEL courses, results and findings – with remarkable conversation and convergence of concerns and hopes for change. In the discussion that followed about staff burnout, and as one psychiatrist on behalf of his team said, "*Our approach is not working for most people – how can we come on this course?*" We explored how to further develop and support the work across Highland, how to share the successes made, and the possibility of looking at tracking the financial costs of patient journeys with R&D by extracting relevant data from GP databases. All who came were asked for their contact information and for some sense of their future interest. The session was filmed and may be used in the development of the teaching manual work.

A second LEARN also took place in November for both patients and staff exploring the issues of food and the modern epidemics – one of the TheWEL core themes. Dr David Reilly and Dr Audrey Banks spoke of the approach in TheWEL to activating a change in how people choose to eat, with some clinical findings from the early biological pilot objective measures. Then with Professor Charles Clark, ophthalmic surgeon and author of several publications on diabetes, the focus narrowed down on the potential and pitfalls of non-drug diet-related management of diabetes.

These events were filmed and will be made available on the web. A **documentary** process is underway as material to get the story of what people can achieve out into a wider world.

Appendix 4 outlines some of the feedback received from LEARN participants.

6.5.2 The Civic Conversation

Working with Andrew Lyon and the International Futures Forum we have started developmental activity around community expansion using a WEL Civic Conversation in Nairn – with preliminary dialogues to be opened in Spring 2013. making contacting with community leaders and others, including links with the ALISS- Improving Links in Primary Care resources (an IT community sign posting pilot initiative) This will explore the idea of the Fifth Wave, TheWEL approach and

the possibility of a WELtown. The first of the wider community conversations likely to take place in autumn 2013.

6.5.4 Arts Projects

A strong theme through the enquiry has been the interlacing of creative process and healing change. This has included involvement in external spaces and therapeutic environments (as in the hospital design project) as well as creative change within an individual and between people in the consultations. We have been exploring the extension of this project stream, in a community context.

- A partnership with Highland Arts organisations and Highland Council appointed three WELartists to experience the programme and respond to them.
- In 2013 we aim to develop some work on 'The Immersive Arts and the Healing Shift', through engaging with Gary Malkin, Emmy award winning composer, who is now focussed on the relationship and parallels between deeper art immersion and healing process. We will explore the possibility that some of the skills of successful consultation and therapeutic encounter overlap with those needed for immersive artistic process – such as deep presence and creative activation. Gary Malkin's works - e.g. his 'Graceful Passages' - are already in use in palliative and terminal care in some USA centres. In 2013 we aim to bring him to Scotland, arrange a lecture/seminar, make links to the palliative and hospice community, and pilot a WEL journey day with previous participants. As part of the community conversation on wellbeing we will consider some form of event in the town of Nairn with other Scottish workers who are emerging in this field. The cross-disciplinary dialogue will be reported on thereafter.

6.5.5 Dialogues on 'The Challenge of Rollout'

Initial dialogue has developed with other teams on this theme, such as the medical director at the Penny Bron Cancer Centre. A number of UK and international groups are voicing concerns about dilution through dissemination: erosion and loss of core ethos and values whilst engaged in 'rolling out" healing-based and enablement approaches. We will build this conversation and explore if it might be fruitful to create a seminar in 2013.

Chapter 7. The HEALWEL Evaluation Programme

The next section of the report will outline some of the earlier findings of the previous ***Phase I*** evaluation. It will then describe the approach being taken in the current ***Phase II*** evaluation and detail some preliminary findings. As will be seen, the more recent results are confirming that the programmes have resulted in useful impacts on people lives and professional practice.

We would make a framing remark: in the Healing Shift Enquiry evaluation process, we recognise there is a potential tension generated by the current cultural tendency to focus on operationalising aspects of the encounter or course (e.g. techniques used or taught, or nutrition/ how much exercise, outcome measures on scales etc) which are easiest to communicate. Of course, these are very important, but end of consultation or course feedback and findings from some of the interviews, are pointing to the deep inner processes people experience in healing shifts, with embodied, hard to articulate, changes, and for some, almost existential, transformative movements in the nature of self and past suffering. Some of the participant quotes offered later within this report give a certain feel for this.

7.1 Extracts of *Phase I* Evaluation Results (2007-2009)

This evaluation followed participants in the early years of the programme. Please note that The ***Phase II*** Evaluation is studying the since iteratively re-designed courses, and is not limited to people with CFS/ME as in Phase I.

7.1.1 *Phase I* Quantitative Results

Seventy-one patients with CFS/ME consented to take part in the study and completed the first questionnaire. Eight (11%) then dropped out in the first few weeks and so were not eligible for follow-up assessment. Of the remaining 63 patients, 61 (97%) completed the post core WEL questionnaire. Of those entering the WEL, 43 (68%) opted to do the MBCT training.

Forty-three (100%) patients went on to fully complete MBCT and returned the post MBCT questionnaire. Fifty-five (90%) of the initial 61 completed the 3 month post WEL questionnaire. Forty (85% of a total possible of 47) completed the 9-month questionnaire.

The *Phase I* quantitative questionnaire results suggested sustained levels of patient enablement. See figure to the right.

Benefits were also evidenced in coping and wellbeing (e.g. 88% with some improvement, 56% with clear impact on daily living).

Similarly, for most participants, symptoms improved, with half of all participants rating this as sufficient to enhance daily life. In the cohort of 47 people followed up for 9 months, 70% reported some continued improvement in their coping, 60% in their wellbeing and 55% in their symptoms, sufficient to change the quality of daily life in 50%, 47% & and 39% respectively. These changes suggested that the aim of self-sustaining growth of improved self-care and self-management, with resultant enhancement in wellbeing, was being achieved.

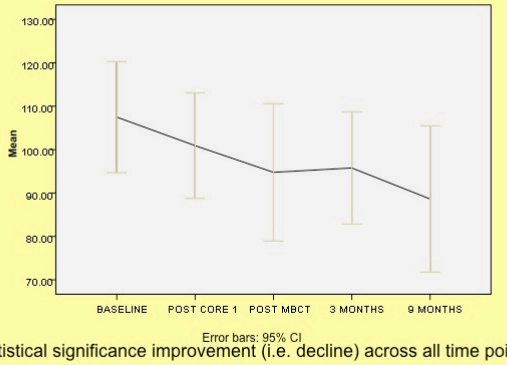
Patient Enablement Instrument

Changes in patient enablement

Previous Work at GHH: Mean Enablement Score was 4.7 (SEM 0.26) 50% higher than the average in primary care. *BMJ* 1999; 319: 738-743.

Fatigue Impact Scale

Changes in FIS



Statistical significance improvement (i.e. decline) across all time points.

The Fatigue Impact Scale showed early evidence of statistically significant change. There was steady improvement in fatigue over time, with enhanced daily life in over half of participants (n24). Moreover, quantitative results suggest improvements in self-care appeared to persist months following the course, suggesting the aim of self-sustained growth was being achieved.

7.1.2 *Phase I* Qualitative Results

Thirty-one patients had pre-WEL interviews. Twenty-seven were re-interviewed at 3 months follow up. Three were lost to follow up, 1 declined and 2 dropped out of the course. Of the 27 follow up patients, 9 participated in a 3rd follow up interview at 9 months.

A purposive sampling approach was taken to ensure that the qualitative sample was reasonably representative of the full database. 70% were female. Ages ranged between 27 and 65. 32% were working and 68% were unable to work. 90% were referred by GPs and 50% suggested the referral themselves. Duration of illness ranged from 2-17 years, with about two thirds of patients' illness over 5 years.

The *Phase 1* baseline qualitative results gave a rich description of the significant personal and health care difficulties the patients had experienced in their journey up to this point. The interview quotes below are part of an article being prepared for submission titled 'Bringing ME in out of the Cold. The article charts participants Health Care journey before the WEL and after. As can be seen, these pre-WEL accounts give a sense of their struggle in a system that did not understand their situation. While these comments are from people with CFS/ME, many echo more general challenges that people with other long term conditions on the WEL say that they face.

7.1.2 – A) The Pre WEL Journeys in the Health Care System

'You think they're (doctors) going to help you and I know they can't wave a magic wand but he (specialist) was so arrogant when I went in… he was really rude and I just felt my confidence and my trust [leave]… I couldn't open up anymore and say 'This is the way I'm feeling'. I just couldn't wait to get out the room quick enough… they've no empathy… some of them, just the way they treat you' (Patient ID 37).

'My whole body was in pain… I had these blinding headaches all the time… I never took headaches like that normally… these things never ended… I have never had a painkiller that worked. I just wanted to know what was happening… I found that hard to deal with… Nobody could tell me what was wrong… I never got diagnosed with anything for 10 months' (Patient ID 51).

'Go home and give yourself a good shake… [Doctors] just give you a dirty look as if you were an idiot. That was some of their attitudes… You could see it in their face that [imitating practitioner- makes dismissive sound]- [I am] an idiot… I have been through 20 years… of doctors ignoring you… 'I'd got to the point I wouldn't go near the doctor regarding it because it was driving me bloody crazy. It was useless going to a doctor' (Patient ID 26).

7.1.2 – B) Post WEL Changes

Follow up interviews after the WEL course revealed that while a few people were challenged by the whole person approach and some course practicalities, there was almost universal endorsement of The WEL model's group format, and staff and service ethos. People reported increased awareness and changed behaviours around self-regard and self-care, incorporated mindfulness and other new practices in daily life, and satisfaction in the group process.

The people who derived most benefit report that they now want to make an impact on their own health and that the course provides the skills and strategies both to make a start on improving their wellbeing, and also plan a longer term journey of improvement. The quotes below give a sense of this 'shift' in awareness and behavior (See 7.4.2 for examples of participants' quotes from a recent StaffWEL course).

'*I used to burst into tears for no reason, it was terrible. Now that's improved… As time has gone on, you say 'God, I used to do that… but I am not doing it now or I'm not doing it as much now'* (Patient ID 51).

'I feel that I am listening to my body better than I would have done before. I think that is something the course taught me: I am worth looking after' (Patient ID 11).

*'I have more control than I had in the past… I haven't got complete control… I still feel unwell… [It is] more in my control but I've not quite got there yet' (*Patient ID 15).

Many participants reported that family members had noticed change in them before they themselves were aware of any evidence of recovery. Nowhere was the 'extraordinariness' of this self-recovery-phenomenon more evident than in how one man chose to express the changes he felt in himself: his self-recovery was recognised in the change in *his cat's* behaviour towards him during a period of meditative 'homework' from the WEL course.

'I'd brought a chair out in the middle of the dining room… I'd have the blinds closed and was sitting in the middle of the floor. The cat wouldn't normally come near you- wouldn't get up on you, wouldn't sit on you even if you lifted her up. I was sitting like that for half an hour and was quite deep and resting. I got the fright of my life! She [cat] was sitting on my knees and nudging my head… It was a strange feeling. Even the cat was beginning to [recognise] 'there's something different about him' (Patient ID 51).

The ***Phase I*** evaluation programme [4] results merited the current developmental ***Phase II*** action-research evaluation programme. In the next section of the report, a summary of the ***Phase II*** approach, alongside some preliminary findings, will be summarised.

[4] Higgins, M., Reilly D., Mercer S., Hopkins D. I. (2009). Evaluation Report of the Pilot Phases of The Wellness Enhancement Learning Programme for Patients with Chronic Fatigue Syndrome CFS-ME. www.thewel.org

7.2 HEALWEL Phase II Evaluation – Methods & Plan

This work is now underway, with the support of the partners mentioned in Chapter 4, building on the previous phase with increased numbers, further quantitative and in depth qualitative evaluation using patient-centred approaches to collect data. This taking place over a three-year period (2012/13, 13/14, 14/15), with analysis and publishing of this phase being completed in 2015.

The evaluation is taking place across three sites: Glasgow (Tertiary Care site, The NHS Centre for Integrative Care); Nairn (Primary Care site, Lodgehill Practice, Nairn Town and County Hospital); and, Forth Valley (secondary care site)**.** The same four-part core WEL programme content and Therapeutic Encounter (TE) courses are being delivered in Glasgow, Nairn and Forth Valley, see Appendix 5.

Building upon and consolidating the evaluation of ***Phase I***, ***Phase II*** extends development and evaluation to participants with a range of healthcare conditions, and health care practitioners in primary, secondary and tertiary care settings. ***Phase II*** began with a one-year Pilot clinical evaluation from 2011. As the results of each year's evaluation emerge, the findings will in turn be fed back into the research process, the further development of the HEALWEL programmes and the development of guidelines for integrative medicine and public health.

The HEALWEL ***Phase II*** evaluation aims to deepen our understanding of the healing journey and the individual's capacity for activating self-healing, recovery and wellbeing. It will seek evidence of embedded qualities of the programmes transferability/ generalisability and scalability across a range of healthcare settings and individuals.

Primary questions of this phase of the evaluation therefore span the five layers described in Chapter 3, and include further work on:

- What are the stages and conditions of healing and recovery?
- How can self-sustaining change be activated and supported – and what is the relationship between self-compassion, healing and recovery?
- How do patient narratives of these healing reactions relate to measurable outcomes of healing and wellbeing?
- How might the programmes enhance practitioners' wellbeing, skills and developments, and thus positively impact patient outcomes?
- How effective are the group based WEL programmes?
- How might they be improved, and useful principles extracted, shared and fostered in today's culture?

7.2.1 Evaluation Methods of Phase II HEALWEL

The evaluation includes the following methods:

A. Literature review of markers of the healing process and their relation to Wellness programmes;
B. Questionnaire-based study of participants on the programmes;
C. Interviews with programme participants;
D. In depth case studies;

E. Focus groups;
F. Pilot study of objective biological measures of healing and wellbeing.
G. Retrospective Questionnaire Study of Past participants of WEL
H. Routine Clinical Evaluation.

7.2.2 Phase II Timescale

Following on from the 2011 Phase II Pilot, the main research study began in Spring 2012, and this phase is running over three years and will be completed in Spring 2015. Funding has been secured for 2012-13 and is being sought at this stage for 2013-2014 and 2014-2015. To-date the project has applied for year on year funding, but a more secure funding base across the Phase II would be valued.

NHS ethics multi-site approval has been granted and the study is registered with R&D in accordance with research governance guidelines. We envisage there being a turn-over of successive cohorts running roughly every three months for three years in the initial stage with the expectation, predicated on successful results, to then request an extension of the development and evaluation period in the future.

7.2.3 Reporting of Progress and Results

Interval results from the 2011/12 pilot year were summarised in the previous submission to the Scottish Government at end of 2011. This Annual Report covers 2012/13 up to January 2013. This will be followed by three further annual reports, thus:

1. Cumulative results of the pilot and year 1 cohorts to be reported in Summer/ Autumn 2013.
2. The cumulative results of, the pilot, year 1 and year 2 will be reported in Autumn 2014.
3. The pilot and Years 1, 2 and 3 results will be reported in Autumn 2015.

In addition, the following will be delivered:

- Progress reports will be available to funders at six-monthly intervals and on completion of ***Phase II***. A full report will also be made available at the end of the project.
- A summary of the study will be added to the Adhominem and WEL-linked website and will be made available to project participants and other interested parties on request.
- Articles will be written and presented for publication to peer-reviewed scientific journals.
- Articles and short pieces will be written and presented for publication in relevant non- peer reviewed journals and web pages.
- The findings of the study will be presented at relevant local, national and international meetings, conferences and symposia.

Progress in delivering this schedule, along with an indication of the kinds of very encouraging outcomes already being observed and reported by participants, is described throughout this paper

7.3 *Phase II* Evaluation Progress

Funding secured from Scottish Government and other funders for 2012 has secured continuation and development of the main clinical programmes that underpin the work. In turn these learning and the action research cycles have allowed continued refinement and re-design of the core programmes. These activities in turn allowed the following evaluation activities

- Begin to deliver its first year (2012/2013), and
- Analyse the early interim results from the ***Phase II*** pilot evaluation, which will in turn underpin the next stages of the study. See Appendix 5 for a summary of some activity.
- Develop Logic Model Planning and Evaluation, as a means of strengthening both evidence based and evaluative approaches; this is being used to guide the planning and delivery of the programme. It provides a means to define and agree shared outcomes, clarify current positions, identify action for future focus and consider evaluative measures and implementation in light of this space. See Appendix 6.

7.3.1 Evaluation Activity Update

A. Literature review of markers of the healing process and their relation to Wellness programmes

The search identified 5882 references that have been assessed to determine whether they meet the inclusion criteria. This identified 683 potentially relevant papers that were then given a detailed assessment, with 121 found appropriate to include in the review. We are now extracting data from these to be entered into a database to allow easy retrieval and synthesis of key findings.

B. Questionnaire-based study of participants on the programmes

We currently have 14 cohorts (8 Nairn and 5 Glasgow) whom we have invited to take part in a questionnaire study (5 time points) looking at the impact of their participation on the WEL programme. Data collection and analysis is on-going and we aim to have interim results to report in February 2013.

C. **Interviews with programme participants**

Twenty eight interviews were carried out with WEL participants in Nairn (13 patients/15 staff). We are planning to complete follow up interviews in Nairn (n 6-10) and a series of purposefully sampled interviews in Glasgow (n 6-10) in January/ February. The interviews have been transcribed and a coding framework developed. 20 interviews have been coded so far and analysis continues.

D. In depth case studies

Three WEL participants are currently recruited for in depth case studies. We hope to recruit three more in January/ February.

E. Focus groups

Focus groups are planned for Autumn 2013.

F. Pilot study of objective biological measures of healing and wellbeing

We have select biological measures from consenting WEL participants (staff and patients). These include fasting insulin, omega 3 and vitamin D levels. By December 2012 some cohorts have reached 3 data points, and others 4. Early results suggest a positive shift in these measures. Analysis is on-going.

G. Retrospective Questionnaire

A Retrospective survey was done on a sample of 150 consecutive Glasgow WEL participants (81% female) with an average length of time since finishing the course of 20 months (median 20, Range 6- 27 months). After 2 follow up reminders we obtained a response rate of 42% (n63). Analysis of these responses, summarised in the Results section that follows, suggest the WEL programme has had a persisting positive impact on participants' lives across a number of different domains (See Appendices 10a – c).

H. Ongoing Clinical Evaluation

On-going end of course feedback from course participants is being gathered and analysed.

7.4 Phase II Evaluation – Example Interim Results

We will now in this section extract some interim results from end of course evaluations, subsequent interview follow-up, a pre-course WEL-influence questionnaire, tracking questionnaires and longer retrospective follow-up questionnaire. We will also briefly mention initial results from pilot biological measures, and give an example case study from a WEL participant. Finally we will end this section with a more external view of the project's results from a Learning Journey conducted by our colleagues in the sister project. To begin with we will offer a brief sense of the results from the Therapeutic Encounter training through an end of course feedback summary – further evaluation will be done in the year ahead.

7.4.1 Therapeutic Encounter Feedback

The unedited feedback summary below offers a sense of the positive impacts being reported by NHS staff after the Therapeutic Encounter Courses. It is taken from the most recent course on 30.11.12 in Forth Valley.

Your Discipline/Role …Nursing - 8, HCSW - 4, OT – 1.

We begin by rating the course overall, then the individual sessions:

THE COURSE overall	Outstanding	Excellent	Good	Adequate	Poor
Overall Value	46% (6/13)	46% (6/13)	8% (1/13)		
Relevance to my work	46% (6/13)	46% (6/13)	8% (1/13)		

Please continue over the page if need be. There is a general comments section first, then a prompt for good and bad aspects:

General Comment?

- Excellent
- After over 20 years in the NHS, a wonderful fresh way of allowing our inner strengths to be discussed and shared
- Found the course excellent makes you step back and think
- The course really awakens your inner thoughts towards delivering the best possible care for your patients
- First class session. Highly informative and thought provoking
- Very interesting and relevant
- Very relaxing environment, very supportive
- Excellent at empowering me to be able to provide therapeutic encounters with patients and to recognize the importance of helping patients to be in control of their own outcomes/findings their own solutions
- Excellent, thought provoking and reassuring

What aspects of this course were especially good:

- Know that I don't have to have all the answers has given more confidence in approaching people
- All
- The gentle approach allowing time to contact
- Enjoyed it all
- Mapping and implications of embedding "maps"
- Layout, No pressure to speak. Not "put on the spot"
- Visual aspects i.e. Slides and video
- Maps – preconceived ideas can be a barrier
- Getting to think deeper into practice and develop it

Please comment if this course has /may affect(ed) your perception/ practice:
Yes 69.5% **No** 7.5% **Unknown** 23%

If your answer is yes can you explain how?

- Make me more aware
- Remembering to listen
- Make me more aware of ME (ie myself)
- More conscious of perceptions, misconceptions and their potential impact on patients
- By listening more, taking time, observe body language verbal/non-verbal
- More empathetic
- More able to help, I'd reflect
- Realise I am in fact doing most of this work but it has increased my confidence
- I feel it has developed my skills as a practitioner especially in my role in palliative care

Suggestions for improvements and/or future planning:
None offered.

Might you want a "Part 2" after this course Yes 93% No 7

- Really enjoyed the course

7.4.2 WEL Course Feedback

7.4.2.1 Patient WEL Course Feedback

On-going end of course feedback is consistently and overwhelmingly positive. A simple current example: the end of patient WEL course evaluation in November 2012 received a rating of Excellent from 54% and Outstanding from 46% and comments like:

- *You have given me such a wealth of advice to follow but helped me realise it's up to me to alter so many of my past thoughts and reservations about myself.*
- *Absolutely loved it.*
- *All the information came to life.*
- *A further building block for me.*
- *It's amazing how once broken into pieces and explained so well that I find hope to help myself cope better with my future worries.*
- *Found this very difficult (in a good way) as I have always resisted facing up to the fact that issues are internal.*

A fuller summary from end of course patient feedback is given in Appendix 7.

7.4.2.2 StaffWEL Course Feedback

Pre-course assessments are highlighting the significant levels of stress in staff and the many challenges to their wellbeing and health.

NAIRN StaffWEL 2. – 31/10/11
22 mixed disciplines16 **(73%) mention mental health challenges** (stress, anxiety, depression, low self-esteem)

7 **(35%) some aspect of metabolic syndrome** spectrum (diabetes (2), obesity/weight (4) angina, hypertension.

The end of course staff feedback is excellent, and even more positive 3 weeks later. The evaluation findings show benefits in terms of personal and professional function and wellbeing. Indeed, other staff, not on the course, have commented on the change in the work atmosphere and efficiency stemming from the course participants. Another important benefit is that adminstrative staff, nurses, and others who refer the patients and prepare them for the programme have done TheWEL for themselves and know the benefits.

StaffWEL Feedback
Sampled at 3 weeks after the course - 93% rated the course as excellent or outstanding

"1. Invaluable in keeping me well so I can continue to work in NHS. 2. Great concepts to use with

The following quotes, from independent interviewing some months after the course, indicate some of the areas in which staff are finding benefit.

'I feel more relaxed… I think it has given me more confidence as well… I do feel much happier… I spend more time listening to what people have to say… Taking more time to discuss their medicines with them, how they feel' (Allied Health Care Professional, 17/01/12, attended WEL programme May 2011)

'I certainly feel better, more gentle with myself, more gentle with other people. My home life has changed, there's no argument... My family life has changed… just so

much less reactive, emotional' (Nurse, 17/01/12 attended WEL programme May 2011).

'The WEL programme helps you to look at people rather than their symptoms. Why is this lady or this man in this condition, why haven't they been able to [use information]? I would say at least 50-60% of them (patients) have had a reasonably good education but it (information) hasn't been taken on board, they actually haven't done anything about it… The WEL programme helps you understand how people can change' (Nurse, 17/01/12, attended WEL programme May 2011).

'I think that course just made me realise a heck of a lot of things about myself…'

I think I'd been too hard on myself for many, many years. A lot of the time I've thought I was a failure, but I haven't really been. A whole weight lifts off you… that's what I got most out of it' (Admin Staff, 22/08/12, attended WEL programme May 2012).

See Appendix 8 for further StaffWEL practitioner end of course feedback and Appendix 9 for staff post course feedback at week+7.

7.4.3 The StaffWEL and Cultural Shift – The PreWEL Influence

Pre-WEL 'Cultural Shift' Effects: 13 of 20 (65%) of StaffWEL participants reported WEL Course Influence from colleagues *before* attending the StaffWEL

- 5 described healthier eating,
- 2 taking more exercise,
- one stopping smoking (supported by the WEL course materials),
- one taking more time-out for themselves,
- and another 'being helped into a state of self-observation'.

It appears we may be succeeding in our goal of modeling a seeding of a shift in a health care culture. We mentioned above that some staff not on the course were commenting on the positive impacts on their colleagues who had attended the course – and we wondered if that might influence these non-attending staff. We then noted an apparent pattern in the pre-course biological measures of the third StaffWEL cohort – some of whose fasting insulin levels appeared to be improving already before the course, between their minus 3 month point blood result and the point of entry result. We decided to explore this by introducing a questionnaire on Day 1 asking about any changes they may have made already in their self-care as a result of influences from the WEL courses, and cross checking with the Nairn co-director GP's knowledge of some of the staff. This suggested 13 of 20 participants (65%) had been influenced by the changes in previous staff participants, and 4 of these also mentioned their WEL-linked GP (Dr Banks) discussing WEL-related ideas. Nine described resultant changes in their self-care (see the side box above).

There are around 280 staff in the Nairn centre, so by the time of StaffWEL5 is complete by February 2013 around 1 in 3 of the staff will have been on TheWEL – the mix of staff is shown in the table below. The nurse manager reported in January 2013 that the effects of this cultural shift were still very evident on her ward, and she had just been at a meeting where the on-going impact of the WEL was being discussed – and staff had been supporting one another in the need for better self-care.

Nairn StaffWEL Professions and Roles (1st 4 cohorts, n=84)	**Number**	**Details – self description**
Nursing and Midwifery	43	20 nurses, 12 CPNs, 4 practice nurses, 4 district nurses, 1 diabetic nurse, 1 health visitor, 1 midwife.
Administration	18	Administrative staff.
Allied Professions	6	2 occupational therapists, 1 physiotherapist, 1 pharmacist, 1 ambulance technician.
Medical	8	6 GPs, 2 Consultants.
Management	5	1 assistant manager, 1 practice manager, 1 public health nursing team manager, 1 cancer care nurse manager, 1 anticipatory care manager.
Ancillary	3	2 health care assistants, 1 cook.
Other	2	2 artists.

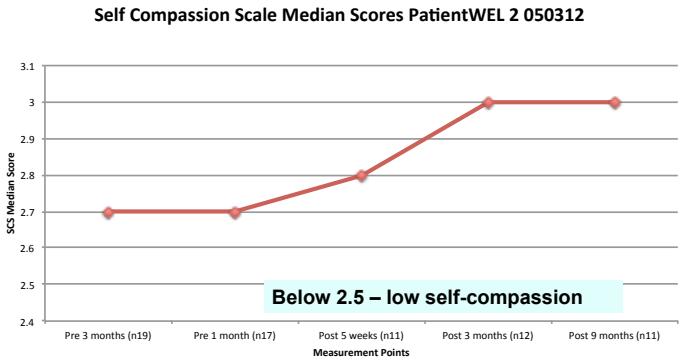
7.4.4 Questionnaire Results

A range of questionnaires are being used to supplement the qualitative data:

- Measure yourself medical outcome profile (MYMOP)
- Fatigue Questionnaire (Chalder Fatigue Scale)
- Outcome related to impact on daily living (ORIDL) (Pre and post WEL version)
- Patient Enablement Instrument (PEI) (Pre and post WEL version)
- Self-Compassion Scale (short form, SCS)
- Psychological Well Being Scale (9 item measure) (PWB)
- + The Group Consultation and Relational Empathy measure (GroupCARE) (developmental only at this stage, completed at week 5 only)

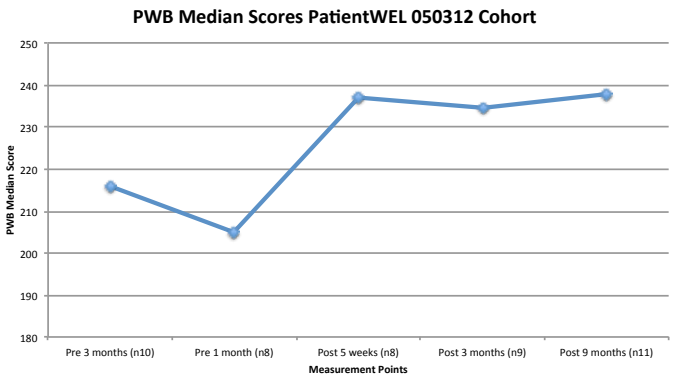
These will be analysed fully in the year ahead. Early descriptive results support the qualitative results, suggesting significantly useful changes – and two examples of early data are given below from a cohort with extended baseline data at -3 months and then point zero.

Self Compassion Scale



Extended Run-in Baseline Descriptive Data - Combined Av. Scores

Psychological Well Being
Nairn PatientWEL 050312



Extended Run-in Baseline Descriptive Data - Combined Av. Scores

7.4.5 Qualitative Interviews with Participants

The next box gives a sense of some formal qualitative results, both from interviews with patients with chronic conditions, including diabetes and with staff working in this area.

Box 4. **Participant quotes**

- 'I cannot praise the benefits of the WEL programme highly enough. I still have many symptoms of ME and I am still learning to cope but I am coping and making progress. I have changed my hours to return to work.... Without WEL I strongly believe that I would be out of work and on benefits visiting my doctor on a regular basis... I know of at least two other women for whom this is also true... On a personal level the gains have been physical, emotional and mental... I would gladly speak publicly about my views'. (Margaret, attended ME/CFS WEL, Glasgow)

- 'The best thing I have ever taken part in' (Lorraine, attended GenWEL, Glasgow)

- 'The wellness programme is the first time somebody has put it (diabetes) in context, and also provided a tool which I thought was incredibly powerful, which was the idea of a map… change the map rather than go on a diet… It just struck me, that's so simple, but at the same time it's incredibly elegant because in explaining that it gave me a way to feel in control of a condition that otherwise is something you feel is not in your control… this actually gave you a lever over your condition' (James, type 2 diabetes, 10 years).

- 'I love fried stuff… potatoes… bread. The problem has been to adjust the map so that you don't do without those things… not quite a treat, but something that you don't eat every day... I don't feel I'm on a diet… So far I've lost about 12 kilos, it's not been an effort… it's just now that's the way I eat' (James, type 2 diabetes, 10 years).

- 'The WEL programme helps you to look at people rather than their symptoms. Why is this lady or this man in this condition, why haven't they been able to (use information)? I would say at least 50-60% of them (patients) have had a reasonably good education but it (information) hasn't been taken on board, they actually haven't done anything about it. Why? The WEL programme helps you understand how people can change' (Nurse).

7.4.6 ObjectivelyWEL - Pilot Biological markers

We have piloted the use of some biological measures with Nairn staff and patient participants to see if we can identify any objective measures that might prove useful in tracking the changes shown in the person-centred evaluation measures, however, we are aware the latter measures are the mainstay of meaningful evaluation of a programme of this nature.

We have started with markers of possible future health change such as Omega3/6 ratios (a marker for future cardiovascular disease), Vitamin D levels (with broad health impacts), inflammatory markers and markers of metabolic syndrome such as fasting insulin levels and blood lipids (linked for example to future diabetes).

Pre-course baseline data are showing concerning results. The staff results are not looking much different from the patients.

Omega3/6 Ratios: There were significantly low levels of Omega3 with only 7 of 110 people (6%) above the minimum recommended 40% Omega3 to total HUFA (Highly Unsaturated Fatty Acids) ratio. It is too early to comment on follow-up changes in the biological markers with any confidence, but we have noticed by October 2012 at 3 Month Follow-up that 31 of 60 participants (52%) had improved to some degree.

- **Fasting insulins:** This a marker for insulin resistance and pre-diabetes and linked syndromes. We have found pre-diabetic levels in around 35% (43 of 119) of participants to date. By week 7 post intervention, 4 of 5 pre-diabetics in the first patient cohort had improved. By October 2012 in +3 months sampling, 14 of 19 (74%) people with initially high fasting insulin showed improved levels. Whilst these results are promising, we would exercise caution at this stage in their interpretation.

- **Vitamin D:** Concerningly low levels. of Vitamin D have been found in around three quarters of the participants. By October 2012, results showed that only 32 of 116 (28%) participants had adequate levels. (The findings showed that of the recent 20 staff members, 56% were deficient in Vitamin D and 38% had insufficient levels).

We would emphasise that these are initial pilot results of surrogate measures, and the initial suggestion of improvements may also wane over time – this will be tested and the issue of sustaining initial change needs to be addressed. If funds can be obtained we would like to consider parallel tracking of a staff cohort without any implied intervention to allow for some comparison beyond our principle model of people acting as their own controls. Further, the WEL model and its evaluation are not predicated on these exploratory measures, rather on direct lived experience of the participants and outcomes that are important to them. This is reflected in the next section.

7.4.7 TheWEL: Retrospective Survey – Longer Term Follow-Up

The ***Phase I*** evaluation had suggested continued benefits in participants 9 months after the course. To see if this could be confirmed, and to get a sense of longer still follow-up, in April 2012, a questionnaire was mailed to 150 people (81% female) who had attended the WEL programme between February 2010 and September 2011. After two follow up reminders 64 people had responded (43%) The average length of time since finishing their course was 20 months (median 20, Range 6- 27 months). . An abstract of the results is given in Appendices 10a-c. The results appear to confirm significant on-going longer term benefits, suggesting that the model's aim of enabling self-sustaining change is succeeding in a useful proportion of participants. Some samples of the questionnaire responses are given in the boxes below.

Box 1. Retrospective Questionnaire- Summary Findings

Longer Term Follow-Up - Summary Findings

Consecutive Glasgow Cohorts (Median 20 months (6-27) (n=61/150, 60% CFS)

'**Strongly Agreed**' or '**Agreed**' TheWEL had positive impact on their:

- Ability to cope with their problem (86%)
- Sense of well being (83%)
- Eating (80%)
- Health difficulties for which they came for treatment (72%)
- Self care (77%)
- Ability to cope with stress (77%)
- Levels of self-compassion (73%)
- Ability to cope with pain (67%)
- Relationships with family(66%)
- Relationships with friend(66%)
- Physical symptoms(58%)
- Relationships with work (56%)
- Fatigue (55%)
- Pain (50%)
- Medication use reduced(42%)

Box 2. Retrospective Questionnaire, Most Important Aspect of Course- Self Help: Comments from respondents

'The WEL programme gave me the tools to use to help me help myself.'

'It made me realise what taking care of myself actually meant.'

'The tools I was taught to use in order to take responsibility for my own health and well being.'

'It really helped give understanding of how and why my body was reacting to the condition and gave lots of coping strategies.'

'The focus on self help... The awareness and new knowledge empowered me to help myself.'

Box 3. Retrospective Questionnaire, Additional Comments- Deep Impact

'This programme helped me change my life, not only in helping me cope with ME but at a later stage to address a period of depression during 2011.'

'I feel that attending the WEL programme… my over-all well being, health and fitness has improved immensely to date.'

'Although I still face physical and psychological challenges before I had no idea how to cope with them. Being told to pace yourself means nothing until you learn how to measure your own wellbeing.'

'Excellent course that has changed my life and my family's.'

7.5 Report of the External Learning Journey

In this final section of evaluation results we now include an abstract of a report written by an external visiting team. As part of the *Cultural Influences on Well-being* project, a Learning Journey took place in January 2012. The purpose was to visit and hear from participants (both patients and staff) in the Nairn WEL programmes. The fuller report is available from www.thewel.org and www.afternow.co.uk.

Summary of findings from a visiting Learning Journey to TheWEL Programme in Nairn Jan 2012

The programme has been successfully used with both individual patients and groups. By 2010, around 700 patients had benefited from the programme and a StaffWEL version for professional healthcare staff began in 2010. In 2011 a PrimaryWEL version was launched in partnership with Nairn Healthcare Group, which has involved 43 staff and 18 patients so far.

We visited this programme over three days in January 2012. We met senior practice staff, and18 StaffWEL participants from a range of healthcare disciplines, and 11 patients. During the course of extended and in-depth conversations with these groups, supplemented by a range of individual interviews, it became clear that we were witnessing evidence of a remarkable qualitative change in participants' capacity for self-care, resilience and wellbeing – staff and patients alike. They recognized their experience as one of a 'healing shift' and described a developing sense of compassion for themselves and for others. Staff had developed greater understanding of and empathy for their patients, and understood the importance of self-work, whilst their patients now understood the healthcare relationship as a joint enterprise, with shared responsibility. The sense of energy and purpose, enthusiasm and renewed meaning in life and work generated by participation in this programme was readily apparent to the observing group.

Although the precise nature of the subtle but deep changes which had evidently taken place sometimes proved hard to articulate, these were nevertheless manifest in patients' new acceptance of their condition and their responsibility for purposeful work on their own health and wellbeing. We also heard of the unexpected but positive effects on family life, not least in terms of healthy eating and improved family relationships. Effects also extended into the working lives of staff participants, where 'care' had a new, deeper meaning. The 'healing shift' appears to be embodied and lived, rather than simply a cognitive change. Participants at all levels were eager to see this approach transferred to the broader community, and other service sectors.

We are convinced that the implications of this approach for public health policy, and for the future of the NHS in Scotland, now deserve the most careful consideration.

Phil Hanlon, Sandra Carlisle, Margaret Hannah, Andrew Lyon, with research input from Desiree Cox, Patrick Quinn, Charles Clarke, Cath Krawczyk

APPENDICES

Appendix 1 PrimaryWEL Referral Guidelines

Aims The WEL will help people challenged by Long Term Conditions by working to help them activate sustained change in their self-care. It blends generic core principles of self-management, CBT, mindfulness, nutrition, stress management and healthy activity. See the attached one page participant leaflet for a short summary.
From Whom? We are happy to receive referrals from all Nairn Healthcare Group doctors and liaison colleagues (eg. psychiatry). A referral form will be available on Vision correspondence. If you are uncertain about a possible referral please contact Audrey Banks (audrey.banks@nhs.net). **Capacity? –** is around 20 places per intake. The WEL team will vet referrals. A decision on the best group balance in terms of the diagnostic mix will be made if referrals exceed capacity. So please tell the patient you "will see if there is space" to reduce disappointment.
For Whom? Consider people not so much by the diagnostic label, be it functional or organic, as the fact they are not 'getting there' despite usual care, and those with high resource demands.
Example Problems? People dealing with Chronic Fatigue Syndrome/ME*, fibromyalgia, diabetes, depression, anxiety, chronic pain, somatising, cancer, stress, and other long term conditions, and complex co-morbidity.
Motivated or Road Blocked? Although best if motivated of course**,** they do *not* need to realise they have a need or potential for these approaches. If they have read the leaflet and are prepared to commit to all parts of the course that is probably good enough. Please do not refer people with active roadblocks that need addressed in their own right, for example:
Exclusion Criteria

1. Active or unresolved diagnostic process, including a belief "something has been missed".
2. A person who is still firmly convinced that their problem can be cured with a medical "fix-it" will be resistant to a self-care model. Wiser to delay and work through the issues as need be to give them a better chance at a later date.
3. Unable to cope with the group situation, or sustain the series of 3-4 hour (mostly sitting) workshops –
    a. Exceeds their physical limits
    b. Exceeds their mental or social limits – for example impaired mental capacity from active psychosis, severe depression, learning difficulties; social phobia; anti-social or disruptive in the group; untreated/poorly controlled addiction; marked vulnerability (eg marked and unprocessed grief/trauma) calling for initial one-to-one work.

* For the parallel research evaluation: for CFS-ME please check separate additional diagnostic criteria and let us know if they match or not. Can still be considered if don't fit.

Appendix 2 Example Participant Pre-Course Information Leaflet

Many of us face real challenges with our health or wellbeing. If you then add a long term condition or stress you end up with a loss of peace, facing symptoms, loss of function and quality of life, and maybe problems like feelings of hopelessness, isolation or loss of self-esteem. The WEL is a holistic programme that aims to help you:

- develop a deeper **understanding** of your challenges and so better **self-management**
- develop skills in creating the best conditions for strengthening your **self-healing**
- help **increase your wellness** and strengthen your ongoing commitment to **self-care**

Your Referral	The first step is that your doctor's letter is checked to see if TheWEL is right for you. If we need more information we discuss this with your doctor.
Your Invite	You will receive your invite usually some weeks before the course. If you have any questions about this please contact Aileen Bain on 01667 422764 Wednesday to Fridays, or email: a.bain@nhs.net
Your Yes or No	You will have to confirm your place as explained to you in the letter of invitation. If you do not respond we will need to give your place to someone else
hile You Wait For The Course:	1. If you would like to discuss any aspect of the programme you can make an appointment with Dr Audrey Banks who is the Co-Director of TheWEL in Nairn Health Care Group. Call 01667 452096 to arrange. 2. You will also receive an invitation to join the research evaluation. This is entirely optional. If you do join you will be invited to get some general health and blood checks and questionnaire measures of your wellbeing.
Arriving At The Course	The date and time and arraignments are on your invite letter. On arrival you will have some forms to fill in so please arrive sharp on time

Your STAGE 1 Course

STAGE I – The Foundations of Wellness. Dr David Reilly, Consultant Physician leads you in half-day meetings co-facilitated with Dr Audrey Banks. The course is backed up by a manual, DVDs, CDs and a website. You will be supported on a journey of exploring new discoveries and approaches to help your self-care and self-healing.

1. **Self-Care**: The limits of the fix-it medical model and the need for change, a different way. Change: the Why's, How's and Obstacles. A Wellness Enhancement Learning approach: the underlying whole person approach, findings from Mind-Body Medicine & Self-Healing. Your Self-Care Relationship: the Core of the Course and self-sustaining change. A model of change-practice: Meditation and Mindfulness: introduced using Heartmath as a way of learning to self-care, and supporting body harmony ('coherence') for relaxation, wellbeing and healing.

2. **Food:** A guided self-refection on what you are choosing to eat – against a backdrop of a fresh way of looking at food. Processed food and the modern epidemics -what impacts on energy, healing, resilience and wellbeing

3. **Supporting Change:** What drives poor self-care and what is needed to change it for the better? Cycles of drain and cycles of healing. How thoughts, feelings, body and behaviour are linked, and what we can do with this for our wellbeing enhancement?

4. **Journey Skills:** Ways of reducing suffering, tension and low mood and improving inner peace and wellbeing through skills in handling thoughts and feeling. Introduction to "TheWork" as an example of questioning thoughts.

A Journey Decision

At this point you will be asked if you want to go on to STAGE 2 "The WEL Part X a few weeks later.
You will also have a chance to request a one-to-one consultation with Dr Banks if you feel that is needed.

Our commitment is to support you through the course as you work to find a better path towards strengthening your recovery, wellbeing and wellness.

Our Commitment Together

Your commitment is to do your best to work with us and practice what you are learning, exploring changes in your self-care and lifestyle, and helping yourself by reflecting on things in your life that may have made your system more likely to break down, or block or slow its recovery, and asking what might now help. **If you accept a place on a course, you must commit to attending the whole of that course. If you have a challenge with this please discuss it with us. You are responsible for asking for any follow-up consultations you think are needed.**

RESULTS

What Can Be Expected? The course is not about a "quick fix" but helps you to change things over the long-term. However our research is showing that the majority of people report helpful changes even by the end of the course, and more so 9 months later. To see the results and learn more you can go to www.thewel.org

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WHAT TheWEL IS NOT.

The WEL is not a therapy group and no one has to tell their story or even speak. It's not about particular illnesses. It's about you taking the space in your life for your own health and coming along to reflect and learn. People can be shy at the beginning but the feedback says people really relax and enjoy themselves. It is not a substitute for one-to-one meetings with a health care worker - so if that is needed it must be arranged separately before or after the course.

Appendix 3 WEL Programme Timetable

– Some elements from Participant Information.

Week	Topic
1	**1st four part module led by Consultant Physician (and a GP in the PrimaryWEL).** The need and search for change and a different approach to long term epidemics and one's own health challenges. The barriers and facilitators of change A Whole Person Approach: Findings from Mind-Body Medicine & Self-Healing. Meditation and Mindfulness: Using meditation (modelled with Heartmath) as a way of learning to produce body harmony ('coherence') for relaxation, wellbeing and healing.
2	Nutrition. Health and food – a fresh approach to the cultural and personal food related diseases. How to correct dips in energy and increase your body's healing and resilience and wellbeing.
3	Sustainable Change - What drives poor self-care and what is need to change it for the better? Cycles of drain and cycles of recovery and healing. How thoughts, feelings and the body are linked.
4	Deeper Skills - Ways of reducing suffering, tension and low mood and improving inner peace through skills in handling thoughts and feeling.
	And In Glasgow Only:
5	**2nd three part module led by Senior Physiotherapist.** Getting to know your body: reconnect with your body's needs and current boundaries. Pacing advice, body awareness work with gentle stretches.
6	How your body responds to stress and anxiety. Balancing your body chemistry using helpful breathing, and understanding your biological clock.
7 8	Thoughts about your body – looking at thoughts about your health and how you will take your self-care forward. Beginning to exercise. Body awareness and relaxation practice Bridge to MBCT.
	And in Nairn Only
Part X	A follow-up, re-enforcement half-day, re-cueing earlier learning, and then emphasising "journey skills" in the long-term challenges of self-care and wellness enhancement.

Appendix 4 THE LEARN Evaluation Summary – 6/11/12

What is the most important thing you will take away with you from today's LEARN?

- So good to hear the information again – "like the teaspoon theory". Would love to take a WEL programme to a group of children – changing the format look at the process from 1st year – 6th year, would be so interesting to see the outcomes.
- How to kill someone and not get caught – insulin! How to kill yourself – sugar/high refined carbohydrates. That there are doctors that think like me and I'm not odd after all! Thank you for a great afternoon.
- Improve health and well being by healing shift enquiry and reducing insulin by reducing carbs.
- I knew quite a lot about WEL and also diabetes however my interest has been restimulated. Thank you.
- How bad my diet/eating habits actually are. Totally shocked at how much sugar is in the food I eat. I knew I didn't have a particularly healthy diet. I need to change and the WEL programme has come at just the right time in my life.
- Importance of rethinking on diets and food intake. Agrees and accepts on "diets" but for the most part fail.
- The focus on real food not societies idea of food.
- An awareness of the importance of what we put in our bodies, how we treat ourselves and what we can do to improve things. I feel enlightened!
- Reduce carbohydrate. Rethink food and advice to patients.
- How dangerous refined carbs are. The danger of sugar.
- That diabetes is a reversible condition. Disturbing role of big business and drug companies. Why is Commonwealth Games being sponsored by Irn Bru? Role of politicians.
- Reflecting on the food advice I will provide. Clinically will take time. Primary advice is lowering carbs.
- That it is ok to eat food just to be more selective.
- Awareness of programme and evidence.
- Fat is good! But a bit confused by my surreal understanding and the "new" idea.
- Think about the food I eat. Think about a meal planner to include food group essentials.
- How bad our diet is.
- Quite mind blowing! Highlighting what we are all doing wrong – Scary. Insulin part very interesting.
- We as health care providers need to fundamentally change our approach to the management of long term/chronic illness.
- Importance of food in relation to health knowledge of effect of food – specific foods. Concern over government guideline.
- Don't eat sugar!
- Not to believe all you read on packet labels! Or Governement! Fresh is best. Good information that can be passed on to my patients.
- 95% of diets don't work! Not rocket science, don't believe all guidelines especially from government – money talks!

- A change in my diet and that of my family, no "diet" just a change in how and what we eat and will pass info onto my patients.
- I think this has been really eye opening. The amount of evidence provided in the talks was great.

We value all feedback from people who attended the LEARN today. How was today? Any suggestions to improve events like this? Any ideas of the type of events we might usually organise?

- Really good – so interesting talks. Stress on its effects of the body etc. Sports people and their health impacts. A debate between the public health group v the WEL approach? The addiction epidemic – how to solve it.
- More of this type of talk open to the public. More WEL programmes.
- This is the first learn I have attended. Thoroughly enjoyed it. Very interesting, very informative. Thank you!!
- Really liked Charles' talk.
- Extremely interesting, made very much sense, answered questions and queries about diets.
- An enjoyable event. Perhaps a larger longer event open to staff and patients, staff who support people in ADL to disseminate a wider highland message.
- Very informative.
- Thought provoking.
- Fantastic day. This should be essential info for school children and upwards. My teenage is a "junk-vegetarian" living off refined carbs – thinking he eats healthily. I wonder what could be cut out from today – 3 hours sitting is quite a lot. Possibly less of Charles – don't know how valuable the eye pictures were. David is a phenomenal presenter.
- Will the recording be on the website?
- Very enjoyable and informative.
- Lots of interesting info. Just to say personally I found sitting for so long was difficult. More breaks would have helped.
- Participation. Tea breaks!
- More time for discussion/questions – though there was a lot of info being given.
- Helpful in all aspects.
- Spread the word!!
- Excellent day. I hope the message can be spread. As much as I resist the use of social media, it is good for this. Is the video available on-line?
- Really good day.
- It seems like a great programme and I think it will be very successful. You are up against big industry though! You need to start with the staff and run WEL courses for staff. There is still so much misinformation out there.
- Very informative – crushing ideas I had of healthy diet/foods.
- Very interesting – changed my idea of healthy diet (cereal and toast for breakfast = 14tsp sugar!) increase frequency of days and increase background info beforehand.
- Educating, good speakers, time passed very quickly. Thanks to all involved.

- I think it has been the most positive PLT session I have attended. As a diabetes podiatrist, I see “defeated” people with foot ulceration seeing life pass them by.
- Very stimulation and interesting – evoked more questions that time permitted to ask.
- I’d like to hear more about the sustainability and engagement with the third sector

Would you be interested in attending future WEL related events?

Everyone ticked the box

We are in process of creating a mailing list for people who have attended WEL-related meetings in order to send updates on future events. If you would like to hear more about the project, its development and future days like this, please leave your email address or contact details below.

Appendix 5 Summary of interim clinical evaluation progress and growth:

1. Nairn

There are 8 cohorts in Nairn. 5 of these are pilot developmental projects following on the work of the Phase 1 evaluation. All but one of these cohorts are still active. Table 1 outlines the 8 cohort timelines and participants.

Table 1. Nairn		
Cohort Date	Cohort Type	Number of Participants
090511	StaffWEL	22
190911	PrimaryWEL	21
311011	StaffWEL	23
050312	PrimaryWEL	21
140512	PrimaryWEL	19
290512	StaffWEL	22
291012	PrimaryWEL	19
301012	StaffWEL	25
	Total	**172**

2. Glasgow

There are five active cohorts in Glasgow. Two of these 5 are pilot developmental projects following on the work in the Phase 1 evaluation. All 5 cohorts are still active. Table 2 outlines the 5 cohort timelines and participants.

Table 2. Glasgow		
Cohort Date	Cohort Type	Number of Participants
190112	GenWEL	14
230212	CFS/ME	12
250512	GenWEL	21
020812	CFS/ME	18
021112	GenWEL	16
	Total	**81**

3. Forth Valley

There is 1 active WEL cohort in Forth Valley. Adding to activity in 2010 and 20122, in 2012 there have been 2 Therapeutic Encounter (TE) courses, a small group-based self-led pilot of TE using the videos and manuals. Table 3 outlines the WEL cohort timelines and participants, table 4 the Therapeutic Encounter participants (most but not all consented to formal follow-up).

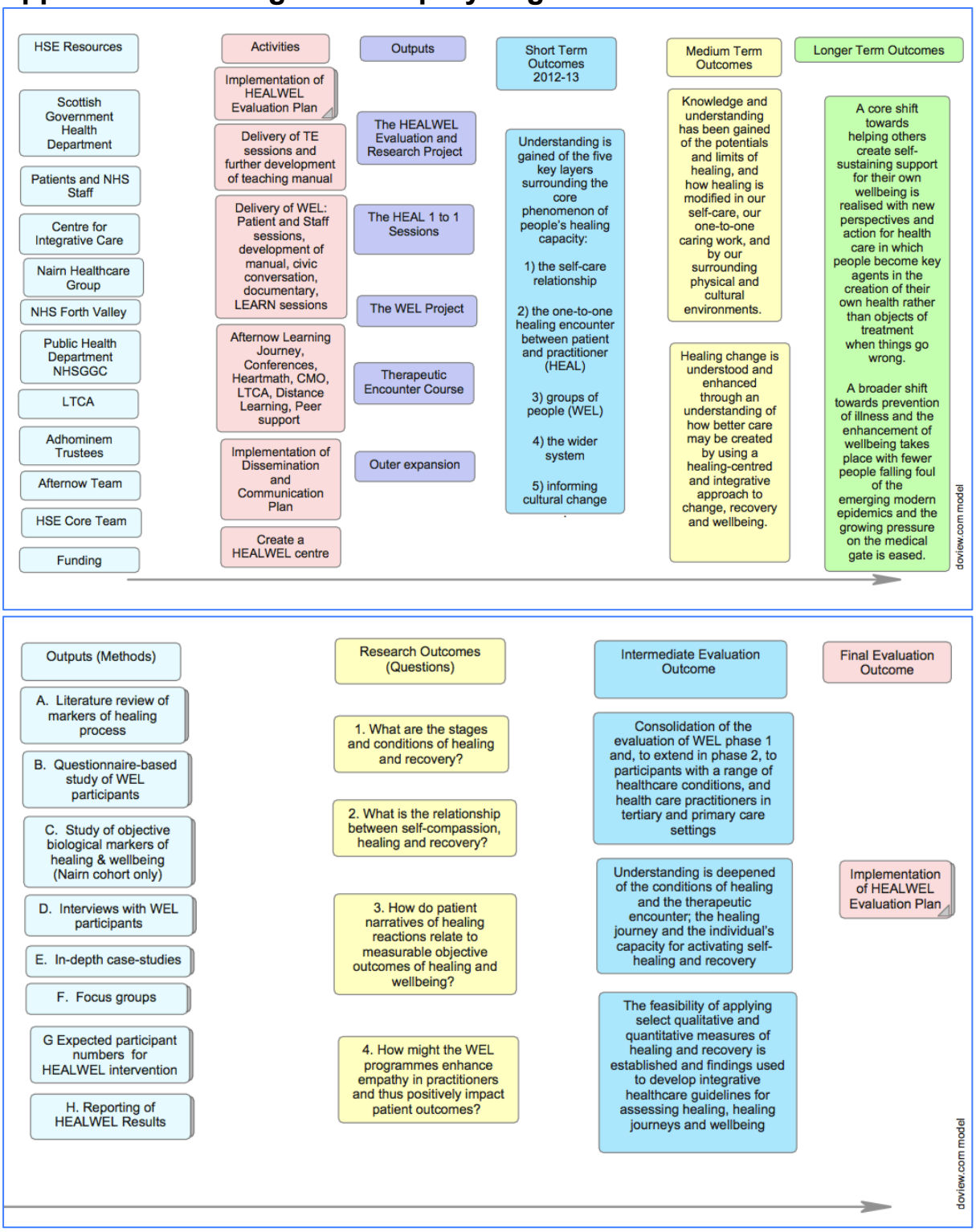
Table 3. Forth Valley		
Cohort Date	Cohort Type	Number of Participants
270412	StaffWEL	11
	Total	**11**

Table 4. Forth Valley (TE)		
Cohort Date	Cohort Type	Number of Participants
220512	TE Part 1	12
301112	TE Part 1	13
071212	TE Part 1 – Self-Led	4
141212	TE Part 2	16
	Total	**45**

HEALWEL Site	**January - September 2012**
NAIRN: Primary Care Site	Prospective Questionnaire study 8 cohorts (Patients/ Staff) 5 intervention points (PRE 3&1 month; POST 5 weeks, 3&9 months) 6 measurements Interview Study (Ongoing) 28 semi-structured interviews Strong testimonies describing benefits of WEL Biological Markers Study (Ongoing) Questionnaire participants invited to have bloods taken 49 staff; 50 patients 4 intervention points (PRE 3&1 month; POST 3&9 months) Measures (amongst others) include: Fasting insulin; HbA1C; Vitamin D; Triglycerides Early results suggest worrying levels of pre-diabetes at baseline, and suggestions of positive shift in these

	pre-diabetic insulin levels. Paper for publication focusing on the fasting insulin results is in development.
GLASGOW: Tertiary Care Site	Prospective Questionnaire Study 5 cohorts (All Patients) 4 intervention points (PRE 1 month; POST 5 weeks, 3&9 months) 6 measurements Retrospective Questionnaire Study Sample of 150 consecutive patients who have attended WEL programme Evaluated usefulness and enduring impact of WEL programme Positive and enduring impact reported across number of domains
FORTH VALLEY: Secondary Care Site	Prospective Questionnaire Study 1 Cohort of StaffWEL Same approach as in Glasgow Therapeutic Encounter Workshop Evaluation of 1 day workshops aimed at NHS clinical staff.
Across all HEALWEL Sites	**Future Work (Jan 2013-2014)**
	Ongoing implementation of current project Evaluation Plans Therapeutic Encounters in Action Video analysis of patient/ doctor consultations Case Series Study In depth study, using purposive sampling approach with patients who have evidenced enduring healing reactions

Appendix 6 Healing Shift Enquiry Logic Model



Appendix 7 TheWEL - The Whole Course: General Comments End of Part 4

GenWEL Feb 2012. Glasgow, 21 patients with multiple long term conditons.

	POOR	ADEQUATE	GOOD	EXCELLENT	OUTSTANDING
THE WHOLE PROGRAMME SO FAR				**10 (48%)**	**11 (59%)**

- Excellent course – back-up material excellent
- Wonderfully enlightening. Have already made changes and those changes have made me feel so much better
- Excellent
- Very privileged to have taken part. It will make a difference to my life and only yet confirm what I believe to be true but needed it "spelled out" to me!
- | I have worried that my thoughts are very repetitive and predictable. Like a hamster on a wheel at times. Is easy enough to step off the wheel. I will continue to step off and look around. The course has helped to open a door for me. I totally get the message. Very liberating. Thank you.
- Very accessible, engaged, entertaining and informative
- I've thoroughly enjoyed the whole course – feeling some benefit already
- Fantastic, will be great to see it rolled out into community in a mindful way
- Very, very good. Everybody should do this!
- Thoroughly enlightening course into how much control the mind has over the body. The DVDs and CD are very useful tools – I have been showing them to my family.
- I paid my teenage son to sit down and study the Part 2 DVD on nutrition – he said it opened his eyes.
- Very helpful in general terms, though not as practical or specific as I expected
- Thank you for helping me to look at myself in a different way – a healthier way
- DVDs should be shown at all schools ….
- I think something ongoing where we can catch up, exchange views and experiences and find out about new research and development
- A valuable experience with lots of thought to take away and develop/practice

Appendix 8 StaffWEL Feedback, End of Part 4

Mixed NHS Staff, Nairn, 2012

- I have already had the confidence to make big changes in lifestyle and work, enjoying giving responsibility to others and not feeling guilty. The course has a very practical easy to understand method. I have been on other courses but this is delivered in such a beautiful way. It's the best time I've spent in many years.

- I started out the course thinking about how to use if for patients but quickly realized how much I needed to do the work – that has been incredibly useful. It has introduced many new concepts and references which I will explore and I am sure use with patients

- This course has changed my life and the lives of my family. It opens my eyes to other possibilities of coping and having a happier, healthier life. This will make it easier to explain to patients and help them if I am going through this myself.

- This course has allowed me to think differently about how others may be viewing themselves. It has also allowed me to step back and give them the opportunity to allow them (the patient) to view their illness/condition without my input/solutions!

- I feel I am on a whole new exciting journey. I have learnt the true meaning of compassion, life and it is OK to feel life, experience your map and journey, allow change, shifting the balance of self-care, nurture and love yourself as much as you love others.

- It does what it says – a fresh approach that is accessible.

- I feel more contentment within myself.

- Definitely experiential – have seen effects of approach on changing my own behaviour – without really trying!

- Has made me consider various aspects of my life. Have found natural change has occurred in various areas. Various health benefits already noticeable.

- Clearly, we are addressing the tip of an iceberg since we all have a lot to explore/examine/address in our personal professional lives. Would be fantastic to have an annual immersive experience to support the process of change.

- By learning to take more time for myself I am more tolerant of others.

- I have never reflected on my views/feelings/self care in this manner before and I think it is going to be a long journey but it feels like a release.

- I have found the whole course very interesting and have come away feeling much better about myself and I think I can cope better with bereavement.

Appendix 9 StaffWEL Feedback, Post course at Week +7

93% rated the course overall as Excellent or Outstanding.

Extracted feedback comments:

- I have started my journey but do need constant reminders to help keep me on my chosen path. Nutrition is a key element for me and this has really made me look at how I am dealing with it, albeit gently does it.
- Very interesting viewing my journey and allow myself just to view and gently guide myself and not push onto others.
- Changes in diet. Change in thoughts already happening able and have shared with others.
- I feel so lucky to have had this opportunity to be on this journey – truly blessed! Thank you …… Life changing!
- Have thoroughly enjoyed all aspects of the course and will certainly help on the journey I have ahead of me.
- 1. Invaluable in keeping me well so I can continue to work in NHS. 2. Great concepts to use with patients – already using them.

Appendix 10a Longer Term Retrospective Questionnaire - Most Important Aspect of Course- Self Help

Longer Term Follow-Up, Summary Quotes

Most important aspect of course- **Self Help**

Consecutive sample of Glasgow cohorts (median 20 months (6-27), n61/ 150)

'The WEL programme gave me the tools to use to help me help myself.'

'It made me realise what taking care of myself actually meant.'

'The tools I was taught to use in order to take responsibility for my own health and well being.'

'It really helped give understanding of how and why my body was reacting to the condition and gave lots of coping strategies.'

'The focus on self help... The awareness and new knowledge empowered me to help myself.'

'Realising that my health, my well being is my responsibility.'

'It helped me understand myself and let me help myself.'

'Self help. Teaching different methods in which the individual can improve his/ her own health without medication.'

'It gave me the understanding to self care.'

'Very helpful in all aspects, gave me a reason to keep going. Felt better within myself. Still have bad days but now better equipped to deal with them.'

Appendix 10b Longer Term Retrospective Questionnaire - Additional Comments- Deep Impact

Longer Term Follow-Up, Summary Quotes

Additional Comments- Deep impact

Consecutive sample of Glasgow cohorts (median 20 months (6-27), n61/ 150)

'This programme helped me change my life, not only in helping me cope with ME but at a later stage to address a period of depression during 2011.'

'I feel that attending the WEL programme my over-all well being, health and fitness has improved immensely to date.'

'Although I still face physical and psychological challenges before I had idea how to cope with them. Being told to pace yourself means nothing until you learn how to measure your own well being.'

'Excellent course that has changed my life and my family's.'

'Even though it has not helped with my fatigue and pain levels I feel this is a programme I would advise anybody with CFS to go on. It has greatly helped my mental well being.'

'I cannot recommend the WEL programme highly enough. It was undoubtably the factor which played the largest role in my recovery.'

'The quality of Dr Reilly's sessions were inspirational and led to significant shift for me.'

'I cannot praise the benefits of the WEL programme highly enough. I still have many symptoms of ME and I am still learning to cope but I am coping and I am making progress. I have changed my hours to return to work... Without WEL I strongly believe that I would be out of work and on benefits visiting my doctor on a regular basis.'

'Very, very worthwhile, and set me on a long but important journey back to 'better' health.'

'The WEL course has helped turn my life around. While I have not recovered my energy levels to what they were pre-ME, I can cope with most everyday tasks and have a better quality of life.'

Appendix 10c Longer Term Follow-Up Retrospective Questionnaire - Summary Findings

HEALWEL PHASE 2 EVALUATION RETROSPECTIVE QUESTIONNAIRE SUMMARY

Aim
To assess the impact on wellbeing by participating on a wellness programme.

Background
In 2005, the NHS Centre for Integrated Care was commissioned to provide a programme of care for people diagnosed with ME/ CFS. The WEL programme emerged in response to this request. The design incorporates current knowledge of, i) the self-healing response, ii) the factors that impact self-healing, and iii) the process of healing change. The WEL is structured as a guided and supported self-learning, group-based programme.

Method
On April 2012, a questionnaire was mailed to 150 people (81% female) who had attended the WEL programme between February 2010 and September 2011. After 2 follow up reminders 64 people had responded (43%). The median time since finishing their course was 20 months (6-27). Three questionnaires were not completed. This gives data for 61 participants.

Results
Positive impacts on wellbeing were seen across a number of different domains.

Summary Findings
84% (n49) of participants reported that they strongly agreed or agreed the programme recognised their illness (based on 58 responses).

84% (n47) participants strongly agreed or agreed that the programme was adequate in scope (based on 56 responses).

88% (n51) participants strongly agreed or agreed that the programme was useful (based on 58 responses).

86% (n50) participants strongly agreed or agreed that the programme was of benefit (based on 58 responses).

74% (n43) participants strongly agreed or agreed that the programme was necessary for their recovery (based on 58 responses).

72% (n43) participants reported an improvement in the health difficulties for which they came for treatment (based on 60 responses).

83% (n50) participants reported an improvement in their ability to cope with their problem (based on 60 responses).

82% (n49) participants reported an improvement in their sense of well-being (based on 60 responses).

57% (n31) of participants agreed or strongly agreed the WEL programme had a positive impact on their physical symptoms (based on 54 responses).

80% (n44) participants strongly agreed or agreed the WEL programme had a positive impact on their sense of well being (based on 55) responses.

42% (n20) participants strongly agreed or agreed participation on the course had a positive impact on the medication (reduced use) (based on 48 responses).

55% (n31) participants strongly agree or agree the WEL programme had a positive impact on their fatigue (based on 56 responses).

50% (n25) participants strongly agree or agree the WEL programme had a positive impact on their pain (based on 50 participants).

67% (n35) participants strongly agree or agree the WEL programme had a positive impact on their ability to cope with pain (based on 52 participants).

76% (n44) participants strongly agree or agree the WEL programme had a positive impact on their ability to cope with stress (based on 58 responses).

73% (n40) participants strongly agree or agree the WEL programme had a positive impact on their levels of self compassion (based on 57 responses).

79.5% (n46) participants strongly agree or agree the WEL programme had a positive impact on their self care (based on 58 responses).

65% (n38) participants strongly agree or agree the WEL programme had a positive impact on their relationships with family (based on 58 responses).

65% (n38) participants strongly agree or agree the WEL programme had a positive impact on their relationships with friends (based on 58 responses).

57% (n26) participants strongly agree or agree the WEL programme had a positive impact on their relationships with work (based on 45 responses).

81% (n47) participants strongly agreed or agreed the WEL programme had a positive impact on their eating (based on 58 responses).