# GENIE

## Implementing and Evaluating the GENIE tool in Southampton Integrated COPD Service

## : A clinical trial and evaluation to ascertain cost effectiveness and patient benefit.

## Introduction

### Background

COPD is a life limiting progressive illness punctuated by acute episodes; prompting potential solutions through self-management support. Clinical trials in COPD self-management have yielded mixed results (Fan, VS 2012 and Bourbeau, 2003.) However, self-management support and education can reduce health care contacts when delivered and targeted appropriately, (Taylor, 2014).

To date the effectiveness of Self-Management Support (SMS) for COPD based for example on action planning alone has been limited ( for example changing utilization patterns) and suggests the need for a more elaborate approach to SMS in clinical settings (Walter J. 2010, Peytremann-Bridevaux 2008 and Taylor 2014).

Decision making processes, as in other conditions may be influenced positively by promoting access to connections and resources through social networks. However to date the concept of socially supportive self-management in COPD has a limited evidence base in terms of how this might be implemented successfully in practice settings.

Long term Conditions (LTC) service within Solent NHS trust includes specialist services for patients with COPD, diabetes and cardiac disease. COPD carries a high symptom burden including mobility limitations and fear of acute episodes of breathlessness; often leading to decreased social interaction, and isolation. Evidence suggests that social interaction acts positively in terms of influencing wellbeing and living successfully with a LTC (Reeves 2014). Isolation has a negative impact on health in general and those with a long term condition in particular. It leads to low mood and an increasing inability to engage with self-care and self-management, and has physiological effects on health (Cacioppo, J 2004). Recent research which explores the nature of consultations with people with COPD suggests that opportunities for engagement with Self-Management Support (SMS) are often missed (Chatwin et al 2014). Moreover, social network connections might be a promising avenue for bringing into focus SMS options that have not previously been explored in professional patient encounters. The latter have been shown to have utility for the mobilisation of resources for self-management and for social involvement likely, to have an impact on self-management and health related outcomes.

Theories of Self-management are based around either the ability to manage a single clinical condition or the ability to manage everyday life; success in these is determined by the ability to fulfil ‘normal’ social roles and the ability to seek happiness in one’s life. The element of social interaction forms the theoretical basis of disease management and health care navigation. For example, adult children are often considered as being pivotal to the social network by the person with the condition. However, the person with the condition is often reluctant to impose a burden of care on children and communicating support needs can be difficult to negotiate when it changes the parent/child relationship .The ability to recognise fractured networks are important when organising and supporting care giving. However creating broader networks within personal trajectories of chronic illness can influence and support people in terms of daily living with a LTC, and support elements of weakness in existing networks.

The maintenance exercise group is a commissioned exercise group post pulmonary rehabilitation. Patients are invited to join a class to ensure they continue to exercise at a prescribed level. This group also provides valued social contact. Continued exercise is vital to ensure physical wellbeing but might be continued outside a clinical setting in a way, which also enhances social contact to replace the social role that the maintenance exercise group currently holds for COPD patients. The current clinical contact time could be replaced by voluntary groups and other exercise providers including informal contacts linked into personal networks of support which might ensure an equivalent or enhanced supportive social environment which is less reliant on existing health care services.

The supportive self-management tool GENIE (Generating Engagement in Network Involvement) has been implemented effectively in a 'My LIFE a Full life' (MLAFL), project, based on the Isle of Wight, (Kennedy et al 2016). The MLAFL programme focuses on people with long-term conditions, older people and those with mental health needs, with three priority areas identified:

- Self-Care and Self-Management
- Crisis Response
- Locality Working

The GENIE implementation purposefully sampled people with type 2 diabetes in order to represent the long-term conditions group. Diabetes is a long term life limiting condition, with episodes of acute illness- during hypo/hyper-glycemic events. However COPD is different to diabetes because of limitations caused by breathlessness which can be physically disabling and socially isolating. Therefore implementing and evaluating this already successful social mapping tool into the COPD service is valuable to understand:

- Differences and similarities in its utility for different Long term conditions
- Barriers to social activity including those linked to a person's physical condition
- Response, uptake and practical benefits of GENIE for COPD patients
- Capacity of voluntary, community and personal network to take on the work previously undertaken in the maintenance clinic.
- Health economic and service utilisation benefits
- Exploration of weak or fractured social networks in COPD

**Purpose**

The main aim here is to increase long term health care management options in Solent NHS Trust by building social capacity to support self-management. The GENIE tool will be introduced into the COPD service to improve options for social groups and exercise when leaving a pulmonary rehabilitation group, or when clinically unable to participate in exercise.

- to build social networking awareness and the importance of utilising existing social resources in the professional and voluntary members of the COPD service,
- to use social network mapping techniques and preference elicitation to engage COPD patients in reflecting on their support preferences and needs, help them access further resources and knowledge
- Evaluate the success of the social mapping techniques (GENIE) in the COPD patient population
- Evaluate the cost benefit to both to patients and to the health service of the GENIE in the COPD patient population

## Objectives

### Primary objectives

Compare and evaluate the health care utilisation and quality of life (burden of disease) in COPD patients using GENIE alongside usual care after leaving the COPD service with those offered only a current practice discharge plan.

### Secondary objectives

Compare and evaluate the change in health behaviours, in particular diet and lifestyle in COPD patients using GENIE alongside usual care after leaving the COPD service with those offered only a current practice discharge plan.

Observe and understand the uptake and utilisation of the GENIE recommendations by COPD patients.

Explore social complexities in the COPD population.

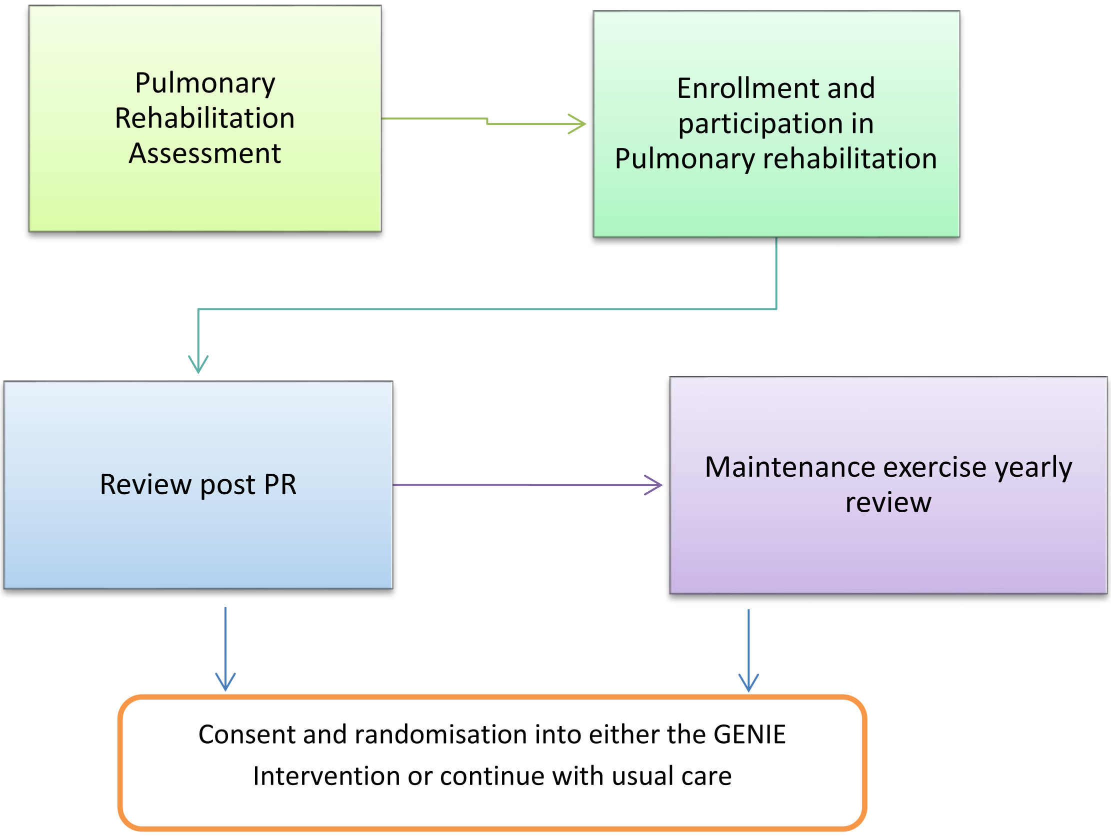
### Implementation Design

This protocol is concerned with the implementation and evaluation of the GENIE tool in the community facilitated by the COPD team and the subsequent evaluation of the GENIE in direct comparison to usual clinical practice.

The researchers will deliver the Intervention with the patients participating in the study at leaving points, during the patient's journey through the COPD service, as specified in the diagram below. Patients enter the pulmonary rehabilitation (PR) section of the COPD service post-acute episode or by GP referral. Patients are then clinically assessed for suitability to continue in the exercise component of the service. If patients are deemed suitable for exercise then they continue onto PR. Post PR they have a review, 30 minutes with a clinician to ascertain their progress through the programme and to recommend continuation of exercise. At this point patients can also leave the programme.

Furthermore patients are offered maintenance exercise therapy – and are reviewed yearly, during these reviews other exercise and activity can also be recommended, patients can also leave the service at this point. These transition points in the care pathway; leaving the PR programme, or at yearly maintenance review patients will be offered to participate in the GENIE study and provided with study information.

1. Those patients completing a PR programme, and in whom we wish to provide clear direction and signposting to appropriate social activity
2. Those who have benefitted from maintenance for 1 year or more, but at review could be encouraged to do more and have more social outlets.



Currently, patients leaving PR classes are usually offered the option to join the maintenance exercise class, delivered by the COPD team, other exercise options are considered, however, these options are currently limited or difficult to access in one place.

**Building capacity to carry out the evaluation:** Ensuring the GENIE database contains an appropriate library of social and health activities suitable for the Southampton COPD patient. The lead researcher will investigate existing exercise, social and community activities, then populate and categorise the GENIE database.

**Introducing the intervention:** In order to successfully implement the GENIE tool into clinical practice; the clinical team needs to be at the core of the process in order to ensure appropriate and effective facilitation. Therefore, the clinical team will be briefed as the study progresses, through question and answer sessions and direct learning opportunities in how the tool works and the objectives of the study.

**Selection and patient information:** Patients in the COPD service; at the outset of their assessment, the end of PR and during maintenance sessions will be informed that the GENIE implementation evaluation is in progress.

Patients participating in these aspects of the service will be offered the opportunity to volunteer for the study, by the clinical team. If patients are interested they can then provide their names to the clinical staff to keep on a secure Solent database. Patient information sheets and invitation letters will be given out to the interested patients at their clinical visits to minimise postal and /or extra visits.

Once patients have received an information sheet, they will be allowed at least 72 hours to read and digest the information, (patient information sheets, consent and GP letters are separate documents), and share this with their friends and family if they wish to. Ideally, patients are provided with information in their clinical visits and are returning for clinical visits then appointments for research could be amalgamated with usual clinical visits. In this way extra study visits can be reduced. Patients, now participants, will be invited to consent and be randomised at the point of leaving usual clinical care. Furthermore, all patients at this point will have the opportunity to opt out of the study.

Once the participant is randomised (using block randomisation technique in clinic), then they will all receive normal clinical care (discharge planning with suggested activities), and the GENIE tool intervention, in the GENIE group, this is in addition to usual clinical care. Baseline questionnaires will also be administered at this visit.

The follow up period will commence 3 months (12 weeks) (+/- 1 week) from the day the GENIE tool was initially delivered. Participants will be invited back, via letter and /or phone call to attend their three month follow up visit at Bitterne Health Centre.

Solent NHS Trust will be the overall NHS organisation with one venue for study delivery; Bitterne Health Centre.

Block randomisation technique, a commonly used technique in clinical trial design to reduce bias and achieve balance in the allocation of participants to treatment arms, especially in this case when the sample size is small (Efird, J. 2010). In order to reduce unconscious bias of the researcher, pre-prepared envelopes containing the possible combinations of group allocation, will be stored in a locked drawer in Bitterne Health Centre. The intention is to randomize in blocks of four, as this will complement the clinic structure. Therefore, each envelope will contain a pre-determined allocation pattern for that clinic (AABB, ABAB, BABA etc.).

The researcher team will share an excel spread sheet which will be set to generate a random number sequence. The next sequential number will be selected, which will then correspond to an envelope with the predetermined sequence. In this way the envelope selection is random, then sequence in the envelopes in also random, but ensures 50/50 grouping of participants. Baseline data for descriptive statistics will also be collected. (Data capture form appended)

In order to conduct meaningful analysis recruitment needs to reach at least 30 patients, in each group, however the maximum could be 60 in each group, 120 patients in total. Therefore recruitment could take between 6-9 months. The timeframe can be increased if necessary.

**Initial / Baseline data collection:**

Socio-economic data will be collected including; disease severity (FEV1), gender, EQ-5D, health care utilisation questionnaire, HEIQ and wellbeing questionnaires (CAT, GAD, PHQ-9), as well as an optional health behaviour questionnaire, from both the usual care group and the interventional group. Please note CAT, GAD, PHQ-9 FEV1 and gender are already captured routinely during clinical consultation.

**Intervention**

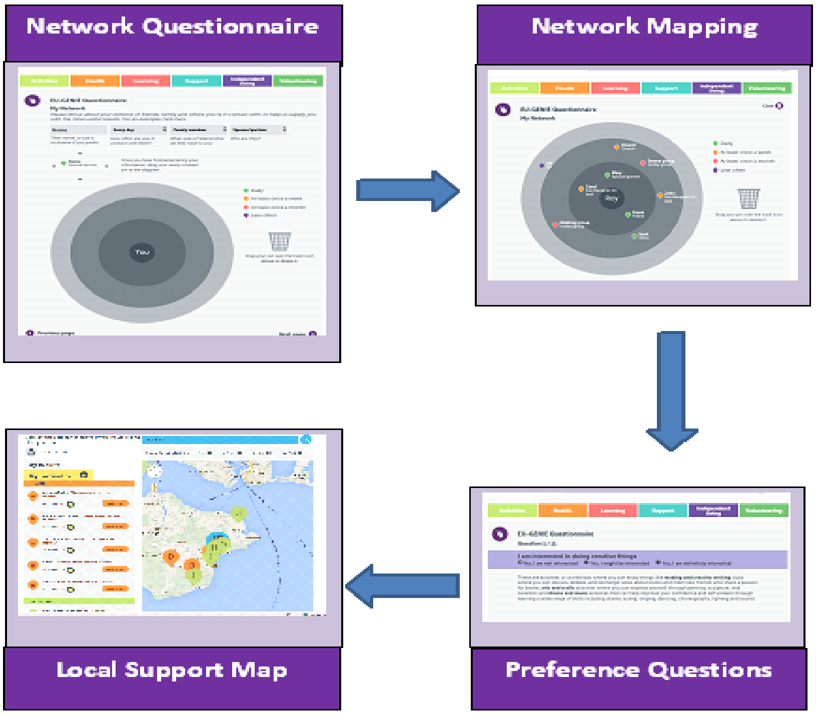
**Assessment stratification and feedback:**

Stage 1: The patient will complete a questionnaire online with the researcher/clinician. The patients will be asked to name the important people and activities in their network, type of relationship and frequency of contact using the concentric circles diagram.

Stage 2: The online process: consisting of series of questions will be used to elicit the participant's values and preferences for activities and support resources.

Stage 3: This section will then link individuals to prioritised and valued activities and resources (links are to a pre-created database where local organisations and resources have been categorised).

Stage 4: The GENIE Tool then presents options in a user-friendly way, on a Google map with clear details about access, an example below:



Both groups will receive usual care, however one arm will have the addition of the intervention both will be called for a review at:

**Three monthly follow up** (+/- 1 week)
Six questionnaires will be administered. EQ-5D, health utilisation questionnaire, HEIQ and wellbeing questionnaires (CAT, GAD, PHQ-9), as well as the optional health behaviour questionnaire, so in 30 participants this will be seven, these will be repeated at 3 months post intervention (+/- 2 week). Furthermore, for those in the intervention arm, feedback and reflection discussions will be initiated using the network diagrams. Participants will be asked again for their permission to tape record these discussions to ensure parity and quality assurance between researchers.

### Analysis of Outcomes

The study gathers data from the intervention arm and the non-intervention arm at baseline and 3 months post intervention. Results will be compared between the groups at baseline and 3 month post intervention. An economic analysis will be performed using a modified version of the Client Service Receipt Inventory (CSRI) (Beecham and Knapp 1999) Medication, health service use will be measured at baseline, 3 months post implementation and follow up. The modified version has been tailored to capture the needs of the target population (COPD patients). The CSRI has been widely used in previous research studies and has been evidenced as a valid measure of frequency of health service use (Patel 2005). The EQ5D is included to assess health status of patients during the GENIE intervention. Wellbeing score (CAT) and HEIQ and in the optional sub-group health behaviours (dietary intake, appetite, alcohol consumption and smoking habits) will be compared at baseline and 3 months. Furthermore, patient uptake of the social activities is to be recorded on paper using the Genie tool and compared between groups.

### Rationale for the service implementation and evaluation design

The implementation and evaluation of the GENIE tool builds on the early GENIE studies indicating that the intervention will work on the premise that finding out about and enhancing network support can be undertaken by a variety of people (e.g. social network members, members of local community groups, health professionals) in a variety of situations (e.g. at home, work, in public and healthcare settings). Further research is indicating the potential of GENIE in existing health care structures, but has yet not been fully tested. Furthermore, much of the preliminary work was performed in patients with Type II diabetes, understanding how GENIE is received in COPD patients requires further investigation.

### Risks / benefits

Each patient leaving pulmonary rehabilitation will be offered usual clinical care; therefore no patient is put at risk. However, it is recognised that the process of divulging and discussing networks and social activity in potentially isolated people, may be potentially distressing. Therefore, the study is still therefore very much grounded within the clinical service. If a person did become distressed, then the interviews and questions would be stopped and the researcher would support the participant in the first instance. The researcher would then be able to refer the participant back into the clinical team, and also request psychological support, through the IAPT / Steps to Wellbeing service, a self-referral psychological service. These participants would also have the option to then withdraw from the study.

The patients in the GENIE intervention arm may have increased benefit due to access and signposting to tailored community resources. Therefore, if a benefit is seen in those participants included in the intervention arm of the study with increased access to services then the GENIE tool will be offered to all patients' post study completion. Ideally, the tool will be implemented and rolled out post study by 'expert users' or participants and or patients who could support others in network support and provision.

## Population

Participation in the study will be offered to every patient in pulmonary rehabilitation or maintenance exercise programs in the east of Southampton. Participants must also fulfill the inclusion criteria. Patients already referred into pulmonary rehabilitation groups will be approached and asked if they wish to participate in the study at assessment and at the end of pulmonary rehabilitation in their post PR review appointment. The appointments are offered to patients after completion of the patients PR program, usually after 12 sessions by the clinical team. Therefore, it is envisaged that a minimum of 30 patients per arm will be recruited; these include PR leavers, maintenance reviews referrals. Appointments will be offered in person, via the telephone with confirmation letter or text. The numbers from each of these groups cannot be predicted as it is dependent on clinical opinion, however the aim to have a minimum of 30 participants, with the aim to recruit up to 60 to ensure meaningful analysis.

Inclusion criteria;

- adults between 18 and 95 with a predominant diagnosis of COPD
- Ability to understand spoken English
- Enrolled in PR or maintenance therapy
- Ability and capacity to make their own decision and consent freely

Exclusion Criteria;

- No clear COPD diagnosis
- Inability to consent

## The Intervention

This evaluation aims to demonstrate the effectiveness and increase social interactions and community networks in the COPD population in Southampton city.

### Rational for GENIE is connecting people to new resources

The aim of using GENIE is to connect people with long-term conditions to local and (in the future) online resources to support them in their everyday lives. Objectives of GENIE:

- Raise awareness of the links and functions that social networks enable (for individuals and local community groups and organisations).
- Use social networks to engage patients in reflecting on their needs and support, support access to further resources and knowledge and introduce practices related to lifestyle, illness management, and behaviour change.
- Strengthen existing individual and community networks and improve patient engagement.

GENIE is a way to help people think about the links they have with others to manage a health problem (local groups, friends, acquaintances, family members, professionals) and to reflect on their involvement in health and wellness activities and their ability to live an ordinary life with a long term condition. By using GENIE and thinking or talking through the GENIE mapping tool, individuals can visualize their network and can reflect on connections that provide value and resources for managing and where there are gaps in support- this might be social, practical or emotional as well as specifically related to a health condition.

**Cost of the intervention**

The service lead has already secured some funded time to enable the GENIE library build the initial database and to deliver the initial implementation research project into the service.

Training on building the COPD sections of the database update in Dec 2016: - following this access to the website https://genie.soton.ac.uk/ and the ability to create a database of local organisations that is accessed by the website.

Initial overview session has taken place in a COPD team meeting on the Thursday 14th April 2016.

## Training Pre Month 0

Training will be delivered by the self-directed support for self-management team who developed the GENIE intervention. The session will take place over an afternoon.

**The GENIE approach consists of three elements**

- Personal network mapping
- Identification of needs and personal interests
- Linking to local resources using website and tailoring to needs and interests through facilitation.

1. **Personal network mapping using concentric circle tool**

   This involves, constructing and visualising a personal network of members and contact supporting long term condition management, four types usually emerge from this process (restricted, family, friend, diverse).

2. **Identification of needs and personal interests by working through preference questions.**
   - Key questions centred on well-being and social needs and preferences
   - Working with personal preferences and need to articulate a set of personal goals

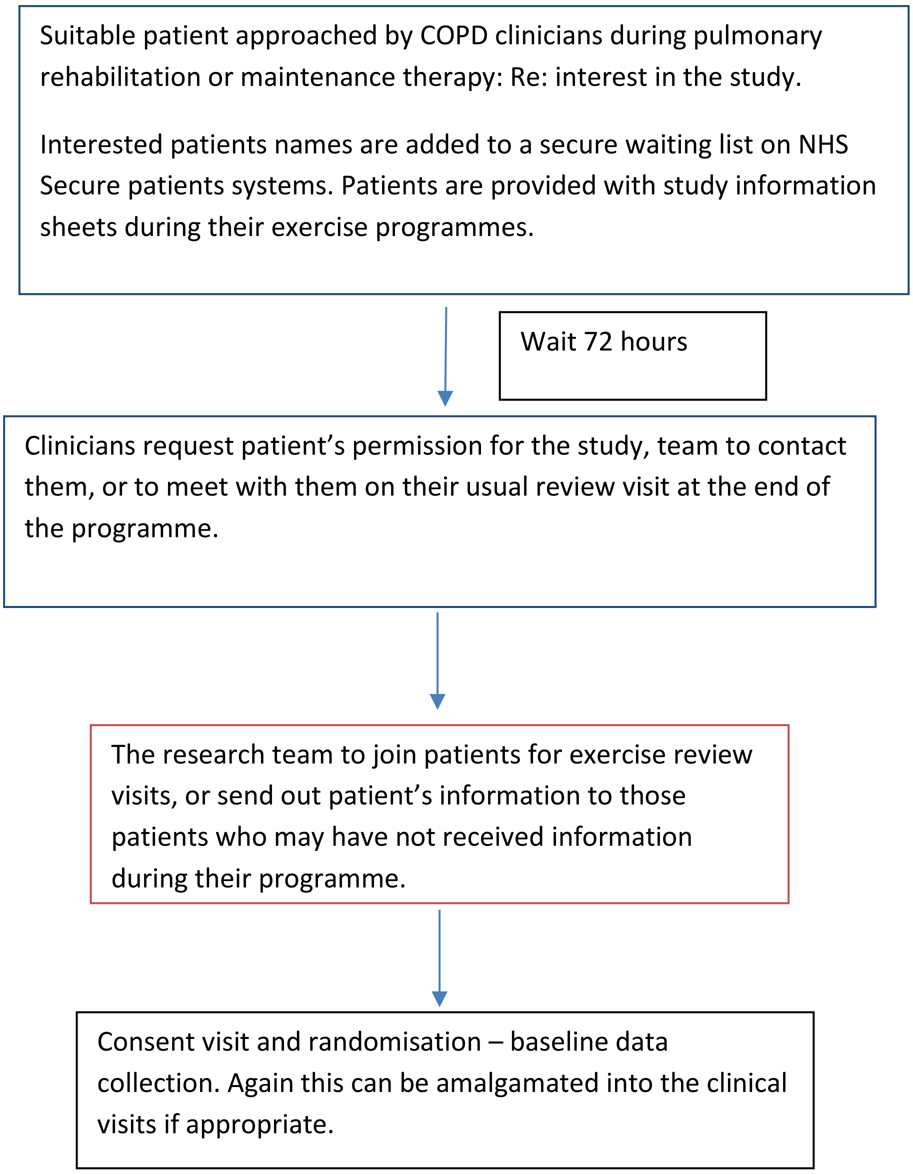
- Link to potential sources of support in community settings through connecting with a dedicated resource.
- In order to maintain privacy, pseudonyms will be used on the website and the printed preferences stored in a locked drawer in Solent NHS space (including pseudonyms of friends and relatives)

**3. Feedback and example**

Following the training, the participants will be given the tools required to roll out the intervention

- Paper and web-based concentric circles with typologies and support suggestions
- Guidebook on how to deliver GENIE
- Access to the database and website

## Identification, enrolment and randomisation



Suitable patient approached by COPD clinicians during pulmonary rehabilitation or maintenance therapy: Re: interest in the study.

Interested patients names are added to a secure waiting list on NHS Secure patients systems. Patients are provided with study information sheets during their exercise programmes.

Wait 72 hours

Clinicians request patient’s permission for the study, team to contact them, or to meet with them on their usual review visit at the end of the programme.

The research team to join patients for exercise review visits, or send out patient’s information to those patients who may have not received information during their programme.

Consent visit and randomisation – baseline data collection. Again this can be amalgamated into the clinical visits if appropriate.

## Table of Events

| | **Consent and Randomisation** | **Pre – intervention data collection** | **12 weeks post intervention data collection** ( +/- 1 week) | **Potential 1 year follow up phase** |
|---|---|---|---|---|
| Consent form discussion and taking informed consent | **x** | | | |
| Randomisation (Block) | **x** | | | |
| EQ-5D | | X | x | x |
| Health Care Utilisation Questionnaire | | X | x | x |
| Socio-economic background / demographic data | | X | | |
| Gender | | X | | |
| Disease severity ( FEV1) | | X | | |
| HEIQ ( Self-management) | | X | x | |
| Optional Health behaviour questionnaire | | x | x | x |
| CAT | | X | x | x |
| Gad-7 / | | X | x | |
| PHQ-9 | | x | x | x |
| Uptake discussion / online survey | | | x | x |

### Quality Assurance

The delivery of the intervention will be taped in as many cases as consented to ensure that the intervention is delivered consistently by the research team to all patients. The tape recording is for quality assurance, and is not intended for research utilisation or publication.

### Future work

The participants included in this initial 3 months of the study could be followed up again in 1 year (12 months) to ascertain longer term outcomes and longevity of connections made. This element could consist of a paper or online survey to understand the uptake rates of the social actives 1 year on, and further investigation into QOL, healthcare use and the option of assessing health behaviours. All participants would be given the option of continuing for a year, and therefore those who continue would be decided by participant preference to remain in the study.

## Analysis Plan

### Primary Outcomes

Descriptive statistics of the cohort,

Descriptive statistics of the cohort will be reported including but not limited to; age, gender, severity of disease then the analysis will be broken down into 5 distinct sections;

a) Pre and post intervention cost utility analysis for the usual care group and the intervention group.

b) Comparative group - pre and post cost utility analysis; calculated cost per QALY (quality adjusted life years) gained and cost of healthcare usage per patient– usual care group at 3 months after leaving the COPD service compared with the post intervention group 3 ( +/- 1 week) months after leaving the COPD service, with significance.

c) Clinical comparative analysis pre and post intervention including burden of disease (CAT score) and psychological impact of the disease, using Wilcoxin Ranked tests. Pre intervention burden of disease correlated with 3 months (+/- 1 week) disease burden post intervention (CAT), with significance.

d) Clinical comparative analysis between groups at 3 months (as above) Wilcoxin Ranked tests.

**12 month follow up survey**

a) Pre intervention burden of disease compared with 12 months disease burden post intervention (CAT).
b) Activity uptake rates; recorded at 12 months post intervention, proportions of patients engaging in recommended activities.

## Ethical Considerations

This is a new research trial of an existing social networking tool already used in long term diseases but not yet specifically in COPD. Prior to introducing this to the entire clinical service, clinical effectiveness recommends changes are trialled on a smaller proportion of the patient population in order to understand the benefits of time and cost prior to full scale implementation.

As this is an intervention within a clinical service and the evaluation is conducted with NHS participants, on NHS properties therefore University ERGO (Ethics) and HRA full NHS ethics application has been sort. The Ethical review number will be on all patient facing documentation. This ethical review has evaluated the social and scientific value of the study. Further to this it ensures adequacy of patient information, the informed consent process, recruitment arrangements and access to information.

The service implementation and evaluation will also be presented at the Solent Adult service line, clinical effectiveness and audit group for Solent NHS Trust approval.

## References

Beecham, J. and Knapp, M. **Costing Psychiatric Interventions. Discussion paper.** Chapter for *Measuring Mental Health Needs.* 1999. Ed Thornicroft, G.

Chatwin, J., Kennedy, A., Firth, A., Povey, A., Rogers, A., Sanders, C. **How potentially serious symptom changes are talked about and managed in COPD clinical review consultations: a micro-analysis**. Social Science & Medicine (2014), doi: 10.1016/ j.socscimed.2014.04.048.

Walters J, Turnock A, Walters EH, Wood-Baker R. **Action plans with limited patient education only for exacerbations of chronic obstructive pulmonary disease**. Cochrane Database of Systematic Reviews 2010, Issue 5 Art No: CD005074 doi:10.1002/14651858 CD005074 pub3 2010.

Patel, A. Rendu, A. Moran, P. Leese, M. Mann, A. Knapp, M. **A comparison of two methods of collecting economic data in primary care.** Family Practice. 2005. Oxford University Press.

Peytremann-Bridevaux I, Staeger P, Bridevaux PO, Ghali WA, Burnand B. **Effectiveness of chronic obstructive pulmonary disease-management programs: systematic review and meta-analysis.** Am J Med. 2008;121(5):433–43.

Kennedy, A. Vassilev I., James, E. Rogers, A. **Implementing a social network intervention designed to enhance and diversify support for people with long-term conditions. A qualitative study.** Implementation Science. 2016

Stephanie JC Taylor, Hilary Pinnock, Eleni Epiphaniou, Gemma Pearce,Hannah L Parke, Anna Schwappach, Neetha Purushotham, Sadhana Jacob,Chris J Griffiths, Trisha Greenhalgh and Aziz Sheikh. **A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS – Practical systematic RevIew of Self-Management Support for long-term conditions.** HEALTH SERVICES AND DELIVERY RESEARCH. Vol 2, issue 53, Dec 2014.

John T. Cacioppo* and Louise C. Hawkley†. **Social Isolation and Health, with an Emphasis on Underlying Mechanisms.** Perspectives in Biology and Medicine. Volume 46, number 3 supplement 2003 :S39–S52. The Johns Hopkins University Press

Fan.V, Gaziano. M, Lew. M, Bourbeau. J, Adams. S, Leatherman. S, Thwin. SS, Huang. G, Robbins.R, Sriram. P.S, Sharafkhaneh. A, Mador. J, Sarosi. G, Panos. R, Rastogi. P, Wagner. T, Mazzuca. S.A, Shannon. C, Coling. C, Liang. M, Stoller. J.K, Fiore. L, Niewoehner. D.E. **A Comprehensive Care Management Program to Prevent Chronic Obstructive Pulmonary Disease Hospitalizations: A Randomized, Controlled Trial.** 15 May 2012. Annals of Internal Medicine Volume 156. Number 10.

Bourbeau J. **Disease-specific self-management programs in patients with advanced chronic obstructive pulmonary disease: a comprehensive and critical evaluation.** Disease Management & Health Outcomes. 2013. 11(5): 311-319

Reeves, D. Blickem, C. Vassilev, I. Brooks, H. Kennedy, A. Richardson, G. Rogers, A. **The contribution of Social Networks to health and self-management of patients with Long-term conditions: A Longitudinal study.** June 2014. 10.1371/ journal PLOSONE.

Efird, J. **Blocked Randomisation with randomly selected block sizes.** International Journal of Environmental Research and Public Health. December 2010.

## Appendices

### EQ-5D

Effective_UK
(English) EQ-5D-5L Pa

## Health care utilisation questionnaire

### *Healthcare Usage Questionnaire*

We would like to know how much use you have made of the health and social services over the last 3 months. If you are not exactly sure, we would rather have your best guess than no information at all.

Please answer every question, even if the answer is ‘No’.

1) Over the last 3 months, if, and how many times, have you used any of the following:

| Type of Service | No | Yes | If yes: Number of visits |
|---|---|---|---|
| GP | | At home | |
| | | In the surgery | |
| | | On the phone | |
| Practice nurse | | At home | |
| | | In the surgery | |
| | | On the phone | |
| Social worker | | At home | |
| | | In the facility | |
| | | On the phone | |
| Visit at home from a community nurse or Dr | | | |
| Specialist community clinic –with consultant | | | |
| NHS Smoking Cessation clinic | | | |
| | | | |
| Other (describe) | | | |

2) Hospital outpatient visit for breathing related issues

| Episode* | Name of the hospital | Reason for appointment | Specialty of Department | Number of appointment* |
|---|---|---|---|---|
| 1st | | | | |
| 2nd | | | | |
| 3rd | | | | |
| 4th | | | | |

*Episode means a visit or group of visits related to a particular problem. Please write down how many appointments you have had for each episode

3) Accident and Emergency for COPD / breathing issues

| Episode | Name of the hospital | Reason for visit | Referral from |
|---|---|---|---|
| 1st | | | GP |
| | | | Outpatient |
| | | | Self-referral |
| 2nd | | | GP |
| | | | Outpatient |
| | | | Self-referral |
| 3rd | | | GP |
| | | | Outpatient |
| | | | Self-referral |
| 4th | | | GP |
| | | | Outpatient |
| | | | Self-referral |

4) Hospital Inpatient for COPD / breathing and chest issues

| Episode | Name of hospital | Ward Speciality | Reason for admission | No of nights* |
|---|---|---|---|---|
| 1st | | | | |
| 2nd | | | | |
| 3rd | | | | |
| 4th | | | | |

*If you were treated as a day patient (day case), then please write 0 under "number of night"

5) Are you currently in paid employment?

No ☐(please go to question 5b) Yes ☐(please go to question 5a)

5a If yes, how many days have you been absent from work because of COPD in the last 3 months?

Please state how many days ☐ 5b If you are not employed:,

In the last 3 months have you had to stop work completely due to your COPD disease

No ☐

Yes ☐

6) Over the last 3 months has a relative or friend taken time off work to look after you?

No ☐
Yes, how many days

7) In the last 3 months, approximately how much additional money have you spent on travel (taxi car park fees and public transportation because of your COPD disease)

None ☐
Yes, ☐ I spent £ ________________________

8) If you would like to tell us about any other costs incurred because of your COPD over the last 3 months (club/gym membership, employing extra help, buying extra equipment, food and meal delivery), please write them here.

No ☐
Yes ☐ I spent £______________please give details ___________________________________