

The Grange Medical Centre

Greenview Medical Centre

Kinsley Medical Centre

Minutes from Patient Reference Group Meeting

Tuesday 16 April 2013– 12 noon

Venue: The Grange Medical Centre Therapy Unit– Hemsworth

Present:

Kate Lamb [KL]	Assistant Practice Manager
John Buttrey [JB]	Patient Representative – Chair
Angie Deakin [AD]	Patient Representative

Apologies:

Rita Harrison [RH]	Patient Representative
Angela Marwood [AM]	Practice Manager
Eleanor Horobin [EH]	Patient Representative

Minutes of last meeting

Minutes of the last meeting were discussed and agreed. The Action Plan from the PRG Survey Results were also made available to the meeting and advised that these were now available at each reception site.

Text Cancellation Service

From the survey results and discussions at the last PRG meeting, a mobile number is now available for patients to cancel appointments. This has been set up as a trial from 15.4.13 and will be reviewed in the future to assess impact on telephone calls. Posters are up on each reception and information screens plus details on the website.

Research One

KL advised details of Research One and provided patient information leaflets about this programme. **(Attached)** There was further discussion and assurances around what happens to patient data, the security of this data and whether patients can opt out of this programme. There is a further information document provided for surgeries which was discussed for further assurances. **(Attached)** The surgery has signed up to this programme and have advertised this on posters and patient information screens. The patient leaflets are available from receptionists when /if patients ask for them.

Other IT Initiatives

KL advised further IT initiatives the surgery is considering to try and improve patient services. These include online services such as repeat prescription ordering, cancelling appointments and patients being able to change their personal details such as telephone numbers. There is a possibility of patients being able to book appointments on line but this will definitely be further down the line.

Appointments update

KL advised the appointments system is currently under review with a view to improving availability of both physical appointments and telephone triage appointments. More details will be available at the next meeting.

Comments and Compliments

This is to be a regular feature on the PRG agenda to review feedback from patients. It has been in operation since November 2012 and KL advised these items are discussed at the line managers meetings. The PRG get an anonymous version of the document and the meeting viewed items listed from Nov 2012 to March 2013. It was commented that there seemed to be a theme of complaining rather than the intended purpose of this document. KL advised that where patient details were provided, feedback is given to patients if appropriate. There were other items mentioned for example disabled parking and pot holes in the car park that have been covered by the PRG and these are areas that will be addressed in the future. There were also some nice comments and compliments made which is good to hear. The full document of items discussed to be added to the minutes of the meeting. **(Attached)**

AOB

None discussed.

Date of next meeting – Provisional date of 11.6.13 from 12 till 2pm *Apologies from John Butt tree as he is away on holiday so requested Angela Marwood Chair the meeting.*

Comments and Compliments

Date	Location	Describe your thoughts	What would be the benefits	Name	DOB
November 2012	Hemsworth	We think your help here is disgraceful. We booked an emergency appointment and have waited an hour.	Emergencies shouldn't be this long.		
November 2012	Hemsworth	Staff should not smoke at the front gate, I have had to walk through them smoking and they didn't move.			
November 2012	Hemsworth	It is really difficult to park your car and can be dangerous and hard to get in or out of the car park.	Bigger car parking area		
November 2012	Hemsworth	Waiting 1 hour and 30 minutes for a form to fill in that took 30 seconds.	People who are here for paperwork do not wait. JOKE		
November 2012	Hemsworth	It is unfair for a doctor to request another pregnancy test <u>only</u> after finding out the process was carried out by 2 females using a private doctor and artificial insemination. A straight woman would not have a digital pregnancy test questioned. I think a bit more awareness of changes in society and fertility in general would be beneficial.			
November 2012	Hemsworth	Need disabled car park, hard to get in and out of car.	Getting out of car.		
November 2012	Hemsworth	Went to see new GP Dr Brown, charming, pleasant, friendly, helpful person he is. Very impressed.	Can we keep him?		

November 2012	Hemsworth	Hemsworth doctors are very good with their patients	Kinsley have had me come down today for blood and they had nothing in, or on their computer.		
Date	Location	Describe your thoughts	What would be the benefits		
November 2012	Hemsworth	Dr Condon is really nice because he helps me get my ears better. It also looks very nice inside here. I like the plants and mostly the pictures that you have up.	Some proper children's books and some more toys would be good		
November 2012	Hemsworth	Good doctors. The people on the 'phones don't listen	I would not have problems being accepted as arrived		
December 2012	Kinsley	Your décor is very dark and depressing. It's enough to make you feel more ill than you really are. Lights are lovely but useless.	For goodness sake, brighten it up.		
December 2012	Kinsley	Some of the women on reception are disgusting, their attitudes towards people, they should not be allowed to look at people and talk down to as though they are better than the rest.	You get more better receptionists not Denise or Sandra the others ought to set them as examples		
January 2013	Hemsworth	The car park entrance has a deep pot hole and needs filling with tarmac. It is damaging to cars and a tripping hazard.			

Entries above discussed at line manager's meeting Feb 2013

Date	Location	Describe your thoughts	What would be the benefits	Name if provided	DOB
February 2013	Hemsworth	Lovely place. Organised, clean, modern, efficient, friendly staff.	I'm grateful that the medical centre is here		
February 2013	Hemsworth	Your request that patients arrive in good time to appointments would be nice if doctors could do the same	Notification of doctor running late would be of benefit. Not all patients have 30 minutes to sit waiting for next appointment for doctor to stroll in unapologetically		
February 2013	Hemsworth	I believe Dr Sweeney is one of the best doctors around. He enables you to feel comfortable and makes it easy to speak about your problems. It is with thanks that I feel better about myself	The benefits in my case have allowed me to discuss my depression and also puts me at ease and makes me feel un-judged and has made it possible for me to feel comfortable to discuss any problems with him		
February 2013	Hemsworth	Yesterday I overheard your reception manager discussing a patient's illness. This is a total breach of patient confidentiality and an infringement that will hopefully be addressed.			
February 2013	Upton	Your service is terrible. The appointments are never on time. It is ridiculous. Make sure your appointments are on time! It is honestly pathetic. Make sure you tell the patient the right time!	There is nothing decent. There would be benefits if appointments were on time. I'll be surprised if you have any compliments.		

February 2013	Upton	Waiting too long for appointments	To make more realistic time for appointments		
Date	Location	Describe your thoughts	What would be the benefits	Name if provided	DOB
February 2013	Upton	Needs to be more doctors up here and hate waiting too long especially with young children	Be better service not waiting too long		
February 2013	Upton	I was very disappointed with the amount of time I had to wait to see the doctor. My appointment was 30 minutes late despite there only being myself and 2 other patients in the waiting room. There were long gaps between patients leaving the doctor's office and new patients going in.			
March 13	Hems	The nurse's hands were shaking; she could not grab the stitches carefully. She pulled sharply one stitch and pulled the skin of the scar apart which was not very pleasant. One stitch I removed myself.			

ResearchOne Information Leaflet for Patients

Introduction

ResearchOne is a database of non-identifiable patient information collected from healthcare settings in England. Some of your anonymous health information is included in ResearchOne for the purpose of research and public health surveillance. The researchers given access to ResearchOne are subject to a duty of confidentiality and appropriate ethical approval. Your right to have your anonymous data excluded from ResearchOne will be respected. This leaflet provides information to answer some of the questions you may have. For further information please visit the ResearchOne website (this is given at the end of this leaflet) or contact us directly by visiting the website contacts page.

What is ResearchOne?

ResearchOne is an electronic database of non-identifiable patient data collected from health records across England. At present more than 20 million patients have the opportunity to contribute non-identifiable healthcare data. Researchers with ethical approval use ResearchOne for health and surveillance research. Information about current and previous research projects is available on the website. ResearchOne is an invaluable resource for public health research due to the depth, relevance and quality of the data stored.

How am I Involved?

Your healthcare provider uses the TPP SystmOne clinical system to maintain your electronic patient record. This contains the details of your treatment and medical history in order to help provide you with high quality healthcare. Anonymous data from this electronic patient record is transferred to ResearchOne to facilitate medical research and to benefit public health. No identifiable details, such as name, date of birth, address or NHS number are transferred to ResearchOne. No notes made in your record will be included in ResearchOne.

Each patient who contributes data is helping to create an invaluable research resource, representing an accurate picture of public health across England.

Why does my Health Care Provider Contribute Data?

Your healthcare provider has chosen to contribute to ResearchOne in order to support quality, high-impact medical research, to drive innovation and to deliver the best possible health care for everyone. ResearchOne also helps your provider to improve the quality of their electronic records and to get early access to new risk prediction and decision support tools, for example.



What Type of Data is on ResearchOne?

Selected healthcare information from electronic patient records is included on ResearchOne. This includes current and past medication, diagnostic codes, allergies and sensitivities, laboratory results and vaccinations, for example. A full list of the stored data types is available in the database protocol on the ResearchOne website. No information that could identify you or your healthcare providers is available to researchers. In order to provide an even more comprehensive research environment, the information may be linked with hospital and disease registry data. This is will only be done if the appropriate ethical and governance authorities have approved this data linkage. Patient confidentiality remains the highest priority and is never compromised.

Who Runs ResearchOne?

ResearchOne is run by TPP as a not-for-profit enterprise. TPP manage the patient health records in the SystmOne clinical information system used by your healthcare provider. TPP store all data in fully NHS accredited centrally-hosted secure data centres. This provides the highest possible security level for data storage and access.

Who Monitors ResearchOne?

ResearchOne is developed with the approval of the NHS Research Ethics Committee and subject to their ongoing monitoring. Governance advice is provided by the National Information Governance Board for Health and Social Care and ensures the necessary safeguards for the appropriate use of patient information. The database protocol, including the confidentiality agreement and guidelines for researchers, is available on the ResearchOne website.

There are two committees which govern the management and use of the information. The ResearchOne Database Committee monitors all actions involving ResearchOne and includes patient representatives, GPs, healthcare providers, academic members, researchers and TPP directors. The committee members have years of experience in the medical research sector and the governance and ethical issues which surround it. An additional ResearchOne Project Committee ensures that all research is of high quality, is relevant to current public health initiatives and does not breach patient confidentiality.

Who uses ResearchOne?

ResearchOne is used by medical researchers who have ethical approval from the NHS Research Ethics Committee and any additional appropriate governing bodies. The ResearchOne Project Committee is in place to guarantee that approved projects will be of benefit to public health across the NHS. Researchers will only have access to minimal set of information needed for their research to progress effectively.



How is the Data Collected?

Information is entered into your electronic patient record by your healthcare provider. If your provider has consented to share research data and you have not decided to opt out, then appropriate anonymous information is automatically included in the ResearchOne database at regular intervals. This process all happens electronically; patient information is never physically collected or manually entered into the database in order to maintain the security of patient information.

How is my Information Kept Confidential and Anonymous?

All data stored in ResearchOne is non-patient identifiable. Researchers are subject to a duty of confidentiality and their use of the data is constantly monitored to ensure confidentiality. The information is stored centrally and securely in data centres hosted to full NHS security standards. The policies around anonymisation, use and data storage are available in the database protocol available on the website.

What if I don't want to be Involved?

If you do not want your data to be included in ResearchOne then please discuss this with your healthcare provider. They will record your decision to 'opt out' on your patient record and your data will be automatically removed from ResearchOne within a short period of time.

How can I learn more?

More information will be available after the ResearchOne website launch in February 2013:
www.researchone.org



ResearchOne

Information for Healthcare Providers

Introduction

TPP have developed ResearchOne as a high-quality ethically-approved research database consisting of non-identifiable patient data extracted from appropriate records held on SystmOne. Uniquely the database contains data from many different care settings across England, for example GP Practice, Child Health, Community, Out-of-Hours and Emergency Department. The data includes a wide variety of clinical data items including diagnoses, medication, vaccinations, admission and discharge information, drug sensitivities and laboratory results. In order to protect the confidentiality of both patients and health care providers, no patient, unit or user identifiable information is collected and no textual data is drawn besides numerics associated with coded data.

The database is centrally-hosted in secure data centres and accredited to NHS standards. Ethical and governance approval has been obtained the Research Ethics Committee and the National Information Governance Board, respectively.

Why has my Healthcare Unit been Invited to Participate?

All SystmOne healthcare units in England (outside of prison settings) are invited to contribute their anonymous data to ResearchOne. Data recorded in prisons is subject to additional ethical and governance considerations and is omitted from this research project.

It is the decision of each unit whether the anonymised data they enter into TPP SystmOne can be included in the ResearchOne database; data is only included if explicit consent from each unit can be checked and verified.

What Happens when a Healthcare Unit Takes Part in ResearchOne?

If a healthcare unit have consented to allow their anonymised data to be included in ResearchOne, then the data will be transferred into the ResearchOne as part of the next scheduled update. This transfer is completely secure, encrypted and electronic; no data leaves the TPP data centre environments. The data transferred consists of non-identifiable clinical data items, a full list of which will be available on the website provided at the end of this document. Some important other indicators are also drawn from the data including rurality and deprivation ranks, sector level postcodes and month/year of date of birth. All these indicators are taken at a level which eliminates any real, reasonable possibility of identification.



As part of the data extraction each research record will be securely allocated a unique research identifier. This enables important longitudinal research studies to take place. A secure, encrypted link table between a SystmOne record identifier and the research record identifier is stored as part of this process. This allows the potential for future important data linkage, for example to the NHS Information Centre Hospital Episode Statistics. This linkage work can only take place after official ethical and governance authorisation has been given and the work has been approved by the ResearchOne Database Committee. This link table is never made available to research staff.

Who can Access this Research Database, and How?

Any medical researcher who wishes to access the data for a new research project must first assign a principal investigator to the project. The principal investigator must gain ethical approval from the Research Ethics Committee before consideration by the ResearchOne Project Committee. The committee approves the project based on the quality of the research involved and the impact it will have on public health; patient and provider confidentiality are at the forefront of this decision. After approval a minimum data subset for the project is automatically built by the ResearchOne Technical Team. This consists only of non-identifiable, anonymised data. Researchers can access this data set either internally from the ResearchOne environment or request a secure, encrypted external electronic transfer of data.

ResearchOne also has a dedicated staff team who manage database maintenance, storage, update and extraction. All staff members have a current Criminal Records Bureau check, have signed a duty of confidentiality agreement, a confidentiality agreement, have had their employment approved by the ResearchOne Database Committee and are legally and ethically bound by strict information systems security and governance policies.

Further details on the security, confidentiality and audit procedures governing data use and transfer by both approved researchers and staff will be available in the database protocol on the ResearchOne website.

Can a Healthcare Unit Withdraw from ResearchOne?

Healthcare units can withdraw from ResearchOne at any time by contacting TPP. The change of consent status is audited electronically and the data removed from ResearchOne at the next scheduled update. This is guaranteed to be with 7 days of the request.

What are the Benefits of Taking Part?

Healthcare units using SystmOne are contributing to one of the largest electronic patient record databases in the world. By allowing non-identifiable data to be made available for research they are helping to create a high quality research database which provides benefits to healthcare across the NHS. The data is used to help develop and improve risk prediction algorithms and decision support tools, to drive important surveillance work, to discover new efficient ways of working, to help



improve data quality across the healthcare estate and to validate existing research done on other large primary care data sets (for example, QResearch and GPRD). Most importantly, participating users will drive much of the developments and research undertaken by TPP to ensure that ResearchOne is used to address the needs of healthcare providers.

Appropriate results from the research, for example new risk prediction scores or decision support tools, will be built into SystmOne to enable contributing units to benefit directly from this work. Results and tools will also be published under open-source licences and in peer-reviewed journals. Details of all current and past research projects and results will always be available on the ResearchOne website.

Healthcare units that participate may wish to conduct research or surveillance. A ResearchOne Portal will be developed on SystmOne to enhance the simplicity of secure, audited access for clinician-researchers that have gained project approval from the necessary ethics and governance committees.

What Information is Available for Patients?

Example posters and leaflets for patients will be available on the ResearchOne website or can be requested directly from TPP using the contact details below. The posters are used to inform patients that anonymised data from your unit is used for research purposes; if possible, they should be displayed in all areas patients can access.

The patient leaflets contain more detailed information about ResearchOne, including instructions on the patient opt-out procedure, how to discover what research projects are taking place, how the research can benefit the public and details about the management and running of ResearchOne.

Can Patients Opt Out?

Patients at contributing units can choose to opt out of ResearchOne by informing their healthcare provider who should then record a special purpose code on their electronic record. Anonymised data from this patient record will be removed from ResearchOne as part of the next scheduled update. More details about this procedure, including the code to record, will be available on the ResearchOne website.

What is the ResearchOne Database Committee?

The ResearchOne Database Committee represents users, the academic community, the public, the ethics committees, and their respective interests in the database. They oversee all database management and operation.

Membership of the group reflects the need to represent the key stakeholders in this project and the need to engage the NHS, different healthcare providers, users, the public, and the academic community.



Membership therefore includes representatives of the following:

- SystmOne National Users Group (SNUG)
- Academic institutions
- TPP SystmOne users
- TPP
- Research Ethics Committees
- SystmOne patients
- The British Medical Association
- Royal College of General Practitioners
- ResearchOne Project Committee

Details of current committee members and minutes of all meetings will be available on the ResearchOne website.

What is the ResearchOne Project Committee?

The role of the ResearchOne Project Committee is to maintain the high quality and value of research to the medical community and to the public. They must ensure patient and provider confidentiality at all times. Membership includes representatives with a strong background in healthcare, informatics and medical research and includes internationally recognised academic researchers. Again details of current committee members and minutes of all meetings will be available on the ResearchOne website.

Who is Responsible for ResearchOne?

ResearchOne is run by TPP as a not-for-profit enterprise.

How can I Obtain Further Information?

More information will be available after the ResearchOne website launch in February 2013:
www.researchone.org

For any additional enquires, queries or complaints please contact us at TPP.

Email: research@tpp-uk.com

