Guiding Principles for a Dynamic Consent Approach

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= e-consent
Dynamic Consent

1. Personalised, digital interface
2. Individuals can give and revoke consent over time
3. Participants have more opportunities to engage with researchers
4. Greater recognition as partners in the research endeavour
1. exercise autonomy

Different kinds of consents can be given and changed by participants at different times in the translational process.
I agree that any surplus tissue that is removed as part of my medical care can be used by the researchers as part of this study.

I agree that blood and urine samples can be taken for use in this research and understand that there will not be any direct participant commercial benefit from this.

I agree that the research team can contact me to arrange appointments to visit my nearest research facility for blood, urine and height tests every two years until the study is completed.

I agree that the research team can contact me to arrange appointments to visit my nearest research facility for bone density tests every two years and that these results will be made available to me as well as my current GP and hospital doctor, if I have one.

I agree to have punch skin biopsies, and for the skin samples collected to be used in the study.

I agree that my donated samples can be used in genetic research aimed at understanding genetic basis for rare diseases and that any results that are clinically important as judged by the Rudy Data Oversight Governance Committee will be sent to the clinical team caring for me.
2. enable choice

It can be tailored to participants needs so they can choose how, and when, they are contacted enabling active involvement if desired.
I agree that the data that is collected about me during the study may be looked at by the University of Oxford and Oxford University Hospitals NHS Trust, and by researchers approved by the Rudy Data Access Governance Committee, both nationally and internationally that contribute to the aims and objectives of Rudy.

I would like to be sent reminders to complete questionnaires and provide follow up information every 6 months

By
Letter Telephone Text Message Email

I would like to be sent updates on the progress of the study

By
Website Email Letter

At a rate of:
Whenever available Monthly Quarterly Annually
2. enable participation

Different types of research methods of involvement can be used depending upon the study and participant needs.
Timeline & Fracture map now online!

We have recently updated Rudy with new features. You can now add your fracture history to your timeline. To get started click here.

Questionnaires

Every 6 months you will be invited to fill out a selection of questionnaires. These help us to track your health through time, and may offer valuable insights to researchers seeking to understand your condition.

HADS
Hospital anxiety and depression scale
Submitted

FACIT
Fatigue scale for chronic illness
Submitted

Pain
Wong / Baker Faces
Submitted

Rheumatic Illness
PedsQL
Started

Pain 2
PainDetect
Submitted

Quality of Life 2
SF36 Health Survey
Submitted

Sleep
Childhood
3. communication

It enables on-going communication and engagement throughout the lifetime of the research, so new consents and samples can be obtained.
4. transparency

Participants and researchers know how samples and data are being used.
5. accountability

It is possible to easily track the uses of data from the consent.
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