



## **National Commissioning Group for Rare Mitochondrial Disorders of Adults and Children**

### **PATIENT ENGAGEMENT SURVEY 2011**

We are keen to obtain your views on our mitochondrial service in Newcastle/London/Oxford.

As a Specialist Centre, many of our patients travel long distances for appointments and also require the use of local hospitals and GP surgeries for monitoring or emergency care.

We want to use your feedback to determine how we communicate with patients and local hospitals or GP surgeries. We are also keen that patients are involved in making decisions about their care.

We would be grateful if you could complete the following questionnaire and return it in the pre paid envelope provided.

**The questionnaire is anonymous and the information will be treated in the strictest of confidence**

#### **Section 1. The Specialist Mitochondrial Centre.**

The following questions relate to your care at the Specialist Centre

Q1. Are you the:

- Patient**    **Relative**    **Carer**

Q2. What is your gender?

- Male**    **Female**

Q3. What age group are you?

- 16 and under**    **17>30**    **31>55**    **56 and over**

Q4. How far do you travel to get to the Specialist Mitochondrial Centre?

- Less than 10 miles**                       **Between 10 & 20 miles**  
 **Greater than 20 miles**

Q5. How often do you attend the specialist mitochondrial clinic?

- One off appointment**                       **Each Year**  
 **Every Two Years**                       **Greater than every Two Years**

Q6. Were you involved in planning your follow up appointment?

- Yes**             **No**             **N/A**

Q7. Were you given the choice for some of your follow up to be at your local Hospital?

- Yes**             **No**             **N/A**

Q8. Do you have access to a specialist nurse or genetic counsellor?

- Yes**             **No**             **don't know**

Q9. Do you have access to support services at the Specialist Mitochondrial Centre?

- Physiotherapist**                       **Yes**             **No**  
**Speech Therapist**                       **Yes**             **No**  
**Welfare Rights Officer**                       **Yes**             **No**  
**Dietician**                       **Yes**             **No**

Q10. Were you given access to additional information?

- Written Information about your condition**  
 **Service Website details**  
 **Support Groups**  
 **Welfare Rights**

Q11. At the Specialist Centre, did you receive information on the following?

- Diagnosis**       **Treatment/Management plan**
- Prognosis**       **Complications**       **Genetics**

Q12. Was your treatment/management plan discussed with you?

- Yes**       **No**       **N/A**

Q13. If you had concerns about deterioration of condition do you have a contact at the Specialist Mitochondrial Centre?

- Specialist Centre via telephone**
- Nurse Specialist/Genetic Counsellor via telephone**
- Consultant via telephone**
- Specialist Centre e mail**

**Section 2. Local Hospital/GP Surgery**

The following questions relate to care at your local hospital or GP

Q14. Have you been admitted to your local hospital or attended your GP surgery in the last 18 months?

- (i) Local hospital       **Yes**       **No**
- (ii) GP       **Yes**       **No**

For what reason did you attend your local hospital or GP?  
 .....  
 .....

Was your mitochondrial condition relevant to this consultation?

- Yes**       **No**       **Don't know**

Q15. If applicable, how would you rate your local Hospital/GP's understanding of your mitochondrial condition?

- Very Good**       **Good**       **Satisfactory**       **Poor**       **Very Poor**

Q16. Was any treatment/management you received from your local hospital/GP



**Reasonably Useful**

**Unhelpful**

**Very unhelpful**

**Please feel free to comment**.....  
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Q24. Do you have any ideas or comments for improving the communication between patients, specialist mitochondrial centres and local Hospitals/GP surgeries?

**Thank you for taking the time to complete this questionnaire. Please return in the pre paid envelope provided**