

Introducing



15<sup>th</sup> October, 2013

Oxford Centre for Diabetes,  
Endocrinology and Metabolism

GB.DIA.13.09.09I dop Oct 2013



# monster MANOR

**Available to download from Oct 15<sup>th</sup> 2013**

Monster Manor is a free game for iPod, iPhone, iPad and Android that helps families of children (age 6-13) with Type 1 diabetes stay on top of their blood glucose monitoring. It aims to engage children in their health management and improve adherence to treatment while having fun.



# Agenda

## Launching Monster Manor

15<sup>th</sup> October, 2013

19.00 – 21.00

## Location

Robert Turner Lecture Theatre, Oxford Centre for Diabetes,  
Endocrinology and Metabolism (OCDEM)

## Panel members

Stephen Dixon, Sky News Presenter

Richard Lane OBE, President Diabetes UK

Dr Katharine Barnard, CPsychol AFBPsS, Senior Research Fellow, University of Southampton

Dr Katharine Owen, Senior Clinical Researcher and Honorary Consultant Physician, OCDEM

Paul Dixey, Ayogo Consultant, Europe

Mimi Astle, Case Study

18.45 – 19.15	<p><b>Arrivals</b></p> <p>Upon arrival all delegates will be registered. Name badges will be given to speakers only.</p>	All
19.15 – 19.25	<p>Introduction and overview</p> <p>Setting the scene, introduction to the expert panel and housekeeping</p> <ul style="list-style-type: none"> <li>Stephen will also field questions from the floor by directing them to the appropriate panel member and encourage an interactive discussion between panelists as well as between panelists and the audience</li> </ul>	Stephen Dixon (Sky News presenter and moderator)
19.25 – 20.00	<p>Panel presentations</p> <p><b>Richard Lane OBE</b></p> <p>Paediatric diabetes care in the UK and a personal perspective</p> <p><b>Dr Katharine Barnard</b></p> <p>The psychological impact of Type 1 diabetes for children with the condition as well as their carers and family, including barriers to testing</p> <p><b>Dr Katharine Owen</b></p> <p>The role of Oxford AHSN in the evaluation of the App and the role of technology in the self-management of diabetes</p> <p><b>Paul Dixey, Ayogo Consultant, Europe</b></p> <p>The origin of Monster Manor and its future role and validation, featuring a video presentation from Adrian Estergaard, Associate Project Manager &amp; Diabetes Consultant at Ayogo Health</p> <p><b>Mimi Astle, Case Study</b></p> <p>A personal perspective</p>	
20.00 – 20.30	Questions from the floor and open discussion	All and moderated by Stephen Dixon
20.30 – 21.00	Wrap-up and carriages	

Richard Lane OBE  
Diabetes UK

# Children's Care

- The National Paediatric Diabetes Audit 2010-11 reported that
- Only 5.8% of children received all of the 8 care processes recommended by NICE
- Only around 15-16% of children achieve an HbA1c below 7.5% - the level recommended by NICE to reduce risk of long term complications – with one third having an HbA1c over 9.5%
- There has been a worrying increase in the numbers of children being admitted to hospital with Diabetic Ketoacidosis (DKA) – a potentially life threatening short term complication of Type 1 diabetes



# Children's Care cont'd

- Many children say they hate testing more than injecting insulin.
- Many children don't like to test because they then get 'nagged at' if the results aren't "good"
- Studies have shown that many young people (and adults) make up blood glucose test results to show their doctor.

# Diabetes UK – My Life, young people's web section

- “I'm 13 and I've had diabetes for 7 years now. I could just lie about everything and say my life's fine with diabetes and I control it well but me and diabetes are worst enemies.
- Having diabetes is the most depressing thing in the world for a teenager like me. I rebel against everything anyone tells me I should do.”



# Psychological Impact of T1DM: Barriers to Blood Glucose Testing

Oxford, 15<sup>th</sup> October 2013

Dr Katharine Barnard CPsychol AFBPsS

# Suboptimal Diabetes Control

- Many children with type 1 diabetes have suboptimal glycaemic control:
  - 81% 0-11 year olds have HbA1c >7.5%  
(England and Wales); 90% for Scotland
  - 28% have >9.5% HbA1c
  - 86% of 11-16 year olds have HbA1c >7.5%
- Suboptimal control can cause lasting damage: "metabolic memory" - even if control later improves
- Need optimal control from diagnosis!

# Psychological Impact

- Childhood / adolescence is supposed to be carefree
- Diabetes is often seen as a 'life sentence'
- Diabetes requires relentless daily self-management
- Treatment is often painful, inconvenient and difficult to achieve optimal outcomes
- Social stigma increasingly reported
- Challenges with schools

# The Patient: Early Concerns

## First 3 Months

## 3-6 Months

## 6 Months to One Year

### Medical Needs

- Referral to endocrinologist
- Make decisions about what regimen to follow
- **Learn how to test blood glucose** and administer insulin
- **Monitoring of glucose levels**, changing insulin doses
- Check ups with HCPs, dietician, therapist
- Adapt to new routines
- **Monitoring of glucose levels**, changing insulin doses
- Check ups with HCPs, dietician, therapist

### Emotional Characteristics

- **Sadness**
- **Fear**
- **Confusion**
- **Anger**
- Denial/desire to ignore diagnosis
- **Embarrassment**
- Depression
- Gaining **ability** to understand and **cope** with diagnosis
- Desire for independence

### Questions

- **Am I going to die?**
- How will this change my lifestyle?
- What can I eat?
- How will my peers react?
- Stay on same regimen?
- **What happens if** I forget my insulin or become more lax with injections?
- Changing insulin dose?
- End of honeymoon period?
- Future living with diabetes

### Constant Concerns

- Developing related complications
- Changing insulin requirements, possible regimens
- Emergency situations like hypoglycemia, seizures or even death

## + Reinforcement In Practice

- Supports development of age appropriate skills acquisition
- ‘Scaffolding’ from parents in teamwork approach
- Cements tasks e.g. SMBG as ‘routine’ to build on
- Promotes success in behaviour change modification
- Need innovative and exciting ways to engage children
- Need data in ‘manageable’ chunks – easy on the eye

# Thank You. Any Questions?

For further information

contact:

[K.barnard@soton.ac.uk](mailto:K.barnard@soton.ac.uk)



# Introduction to the Oxford AHSN

Dr Katharine Owen

Diabetes Network Clinical Lead

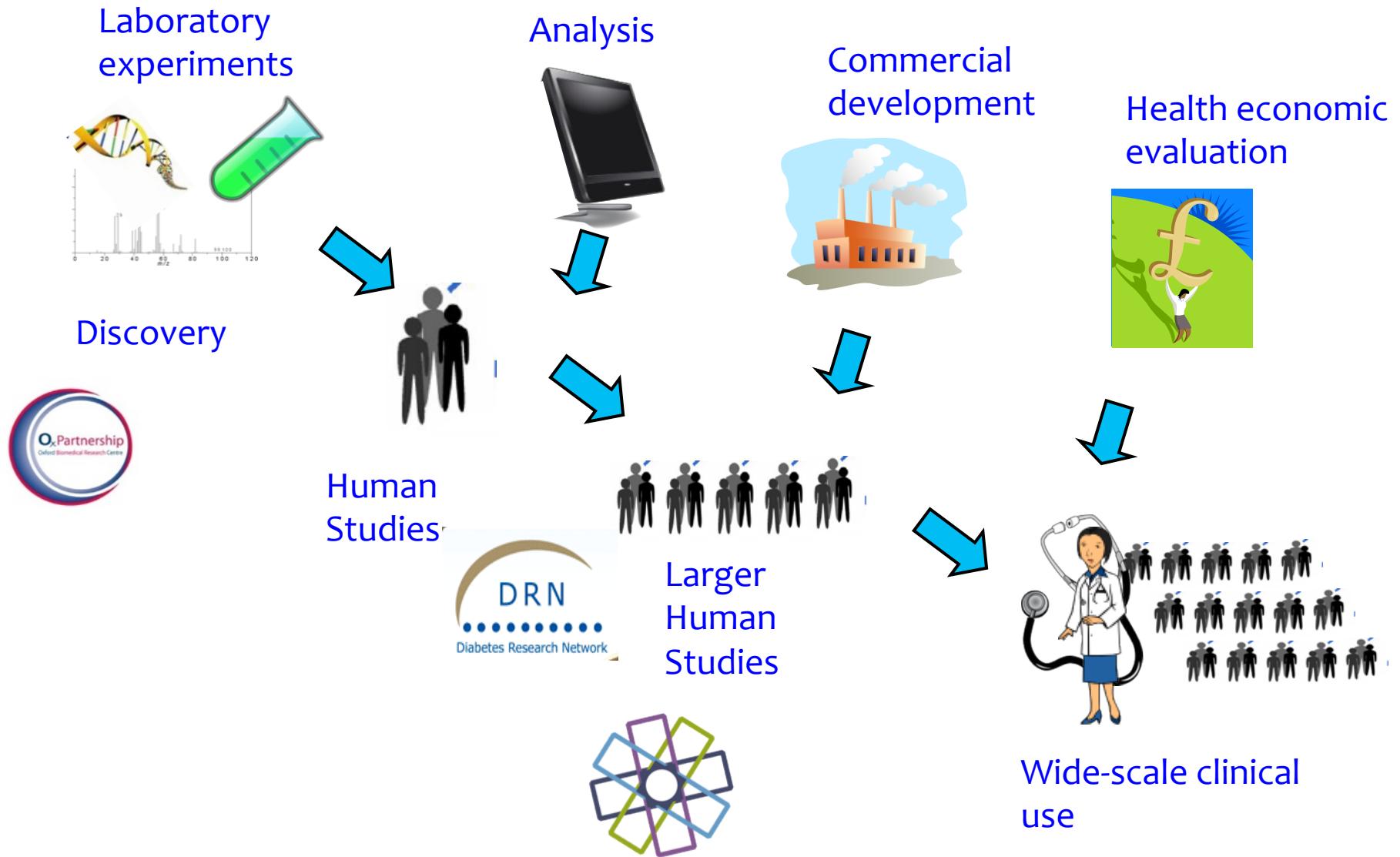
15 October 2013



# What is an Academic Health Science Network?

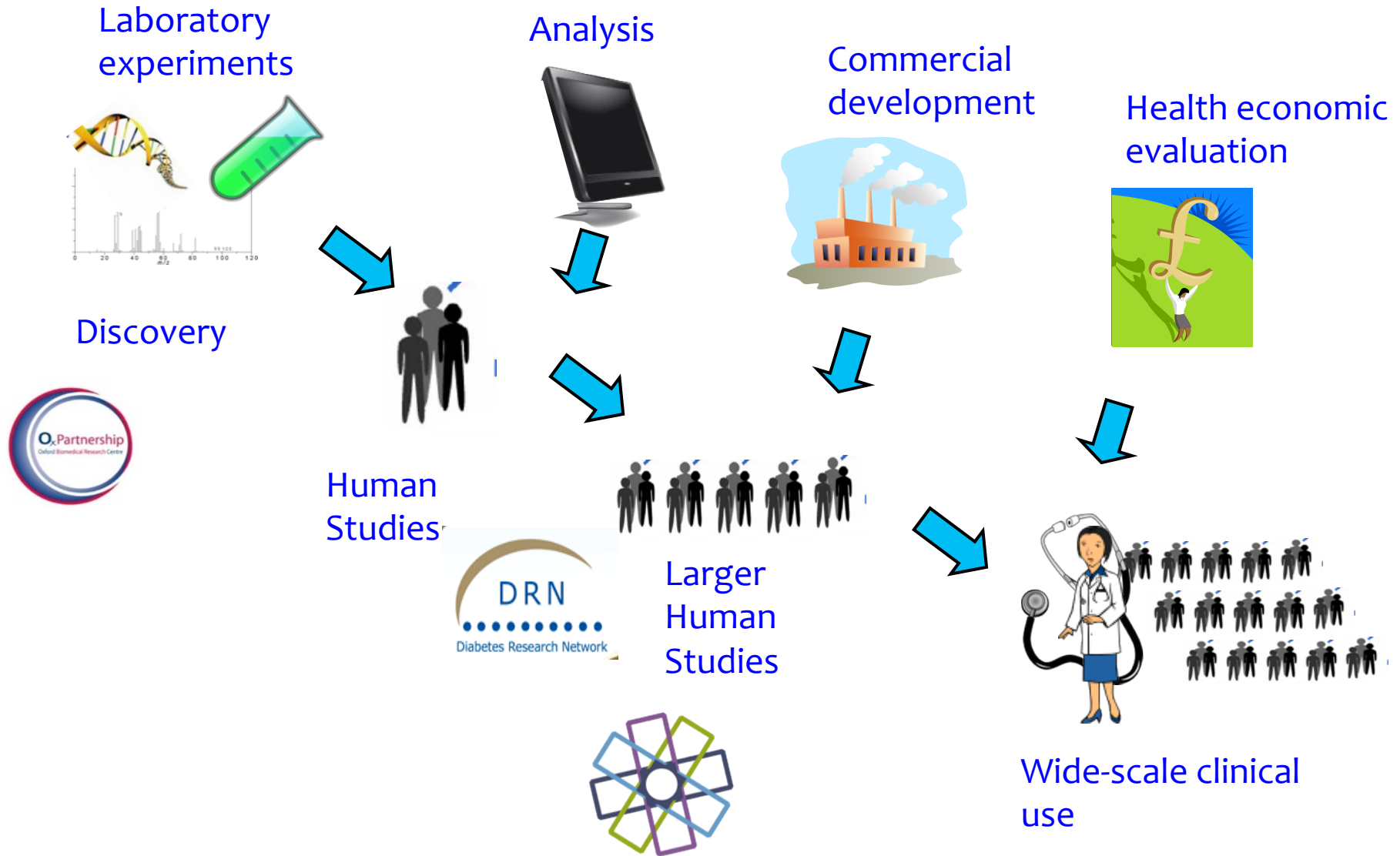
- New organisations funded by the NHS
  - Create partnerships of health, academia and industry
  - Identify health needs and promote best care
  - Speed up movement of research into clinical practice
  - Create wealth by supporting and introducing new products and services
- 





From Bench....

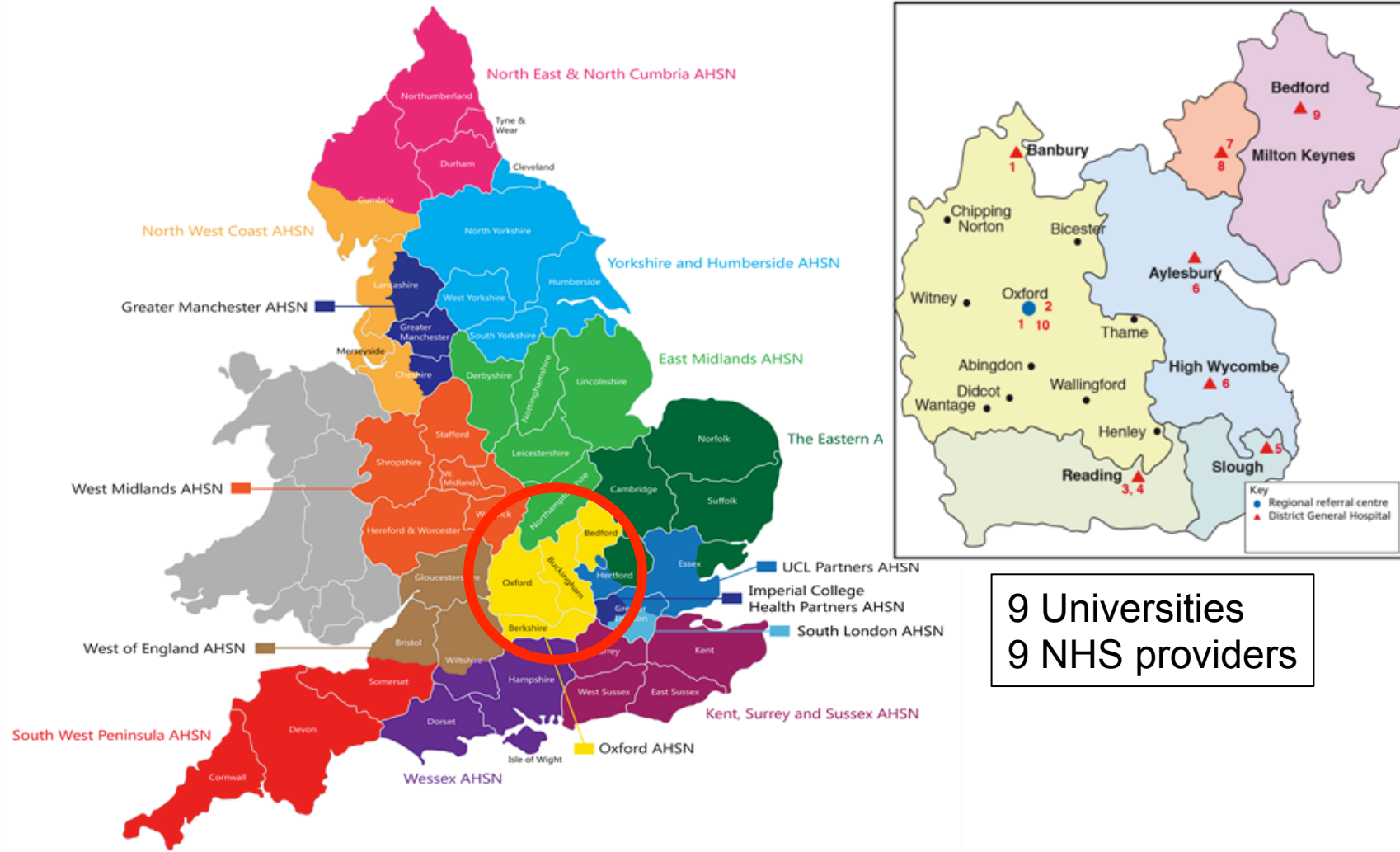
...to Bedside



From Bench....

...to Bedside

# Oxford AHSN – one of 15 nationally



9 Universities  
9 NHS providers

## The Oxford AHSN

- An important aim is providing Best Care through clinical networks
- The Diabetes Clinical Network is the first to be supported
- Why?
  - Diabetes is a significant health problem
  - Diabetes research and clinical care is well-established in the Oxford AHSN locality



# Oxford ASHN Funding Priorities

- Best Care Programme - Clinical Networks:
  - Diabetes
  - Dementia
  - Depression and anxiety
  - Mental and physical co-morbidity
  - Early intervention in mental health
- Continuous Learning – Patient Safety Academy with funding from Local Education and Training Boards
- Patient & Public Involvement Engagement & Experience
- Next – Maternity, Paediatrics, Pharmacy, Imaging and Informatics

# Diabetes Clinical Network Priorities

- Address variation in clinical care and outcomes across the AHSN region
- Evaluate innovative technology for diabetes self-management
  - e.g. #MonsterManorUK
- Young adult clinics
- Islet cell transplant service
- Integrating primary and secondary care for diabetes



# Monster Manor & the Oxford AHSN

- Encourage uptake of the game in local hospitals
- Questionnaire to users before and while playing the game
- Analyse outcome of playing game on frequency of blood glucose testing and see if effect is sustained



Paul Dixey  
Ayogo Consultant, Europe





# Mimi Astle

## Personal Perspective

GB.DIA.13.09.09I dop Oct 2013



# monster MANOR

**Available to download from Oct 15<sup>th</sup> 2013**

Monster Manor is a free game for iPod, iPhone, iPad and Android that helps families of children (age 6-13) with Type 1 diabetes stay on top of their blood glucose monitoring. It aims to engage children in their health management and improve adherence to treatment while having fun.

