

# Diabetes Services for Young People: what do patients think of them?

*Dr Shanti Vijayaraghavan*

*Consultant Physician*

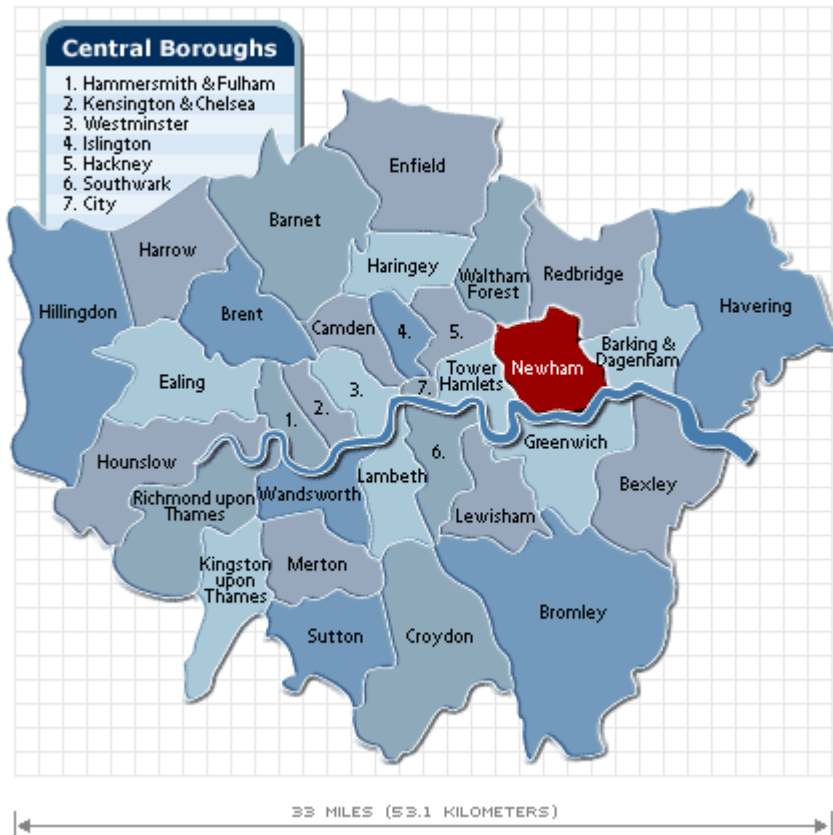
*Newham University Hospital*

*Barts Health*

# Newham – a place of contrasts



# The local population



## Borough of Newham (GLA projections)

- 302,500 (2012)
- Approx. 70% from BME groups, (South Asian ethnic groups being 33%)
- 6<sup>th</sup> most deprived borough in England
- Approx. 40% aged 25 and under (compared to 30% for London)
- Diabetes prevalence 9.4%, 3-4 times national average
- Rising prevalence of T2DM in the young, mainly associated with obesity

# Our figures

Total number of patients (active) on Diamond  
(Diabetes Database) 16-25 years : 219

Type 1 = 162

Type 2 = 46

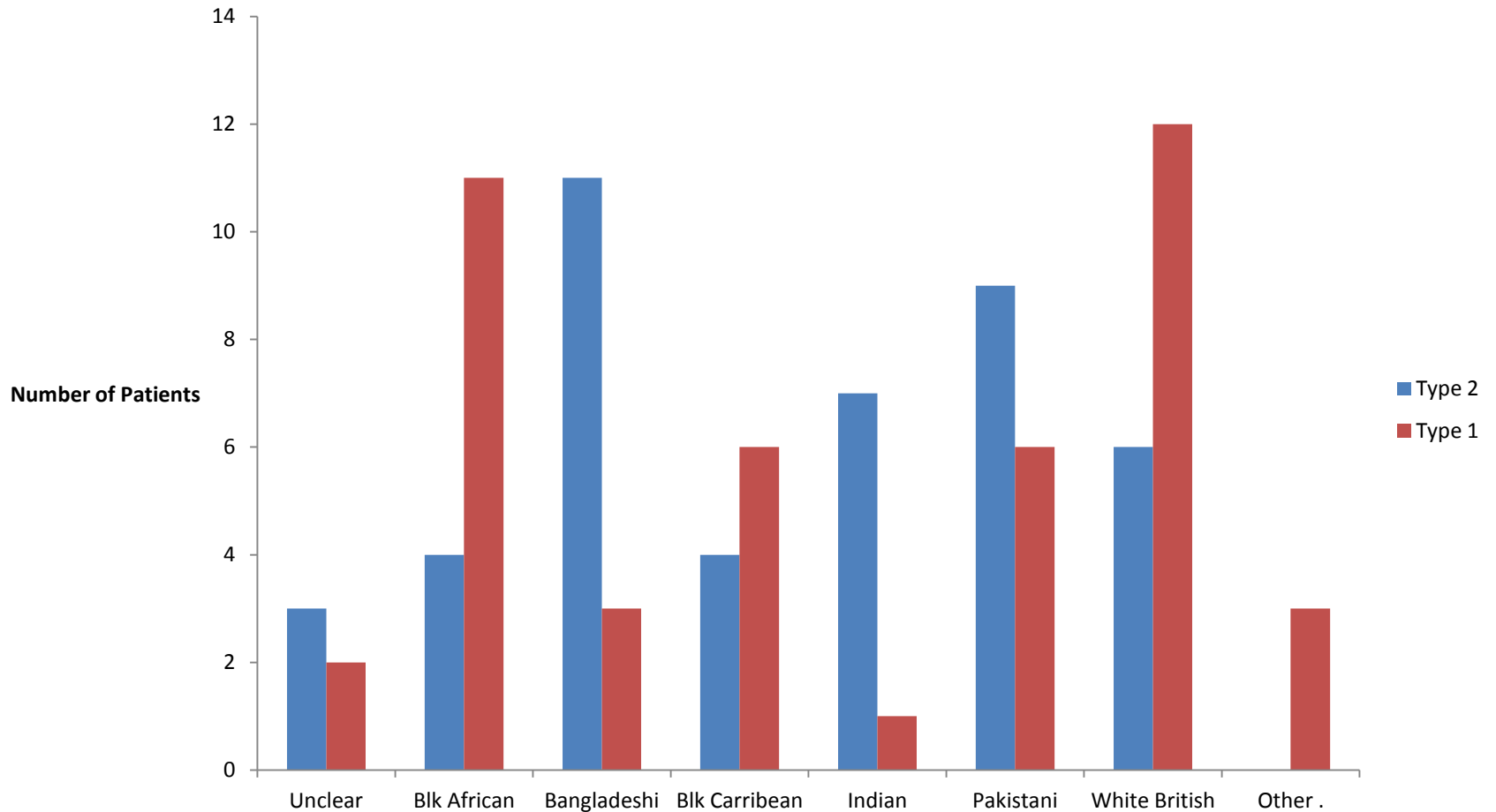
Other = 11

*Type 2 Diabetes in children and young adults in East London: an alarmingly high prevalence. A Balasanthiran, T O'Shea, A Moodambail, T Woodcock, AJ Poots, M Stacey, S Vijayaraghavan. Practical Diabetes June 2012;29(5):193-8*

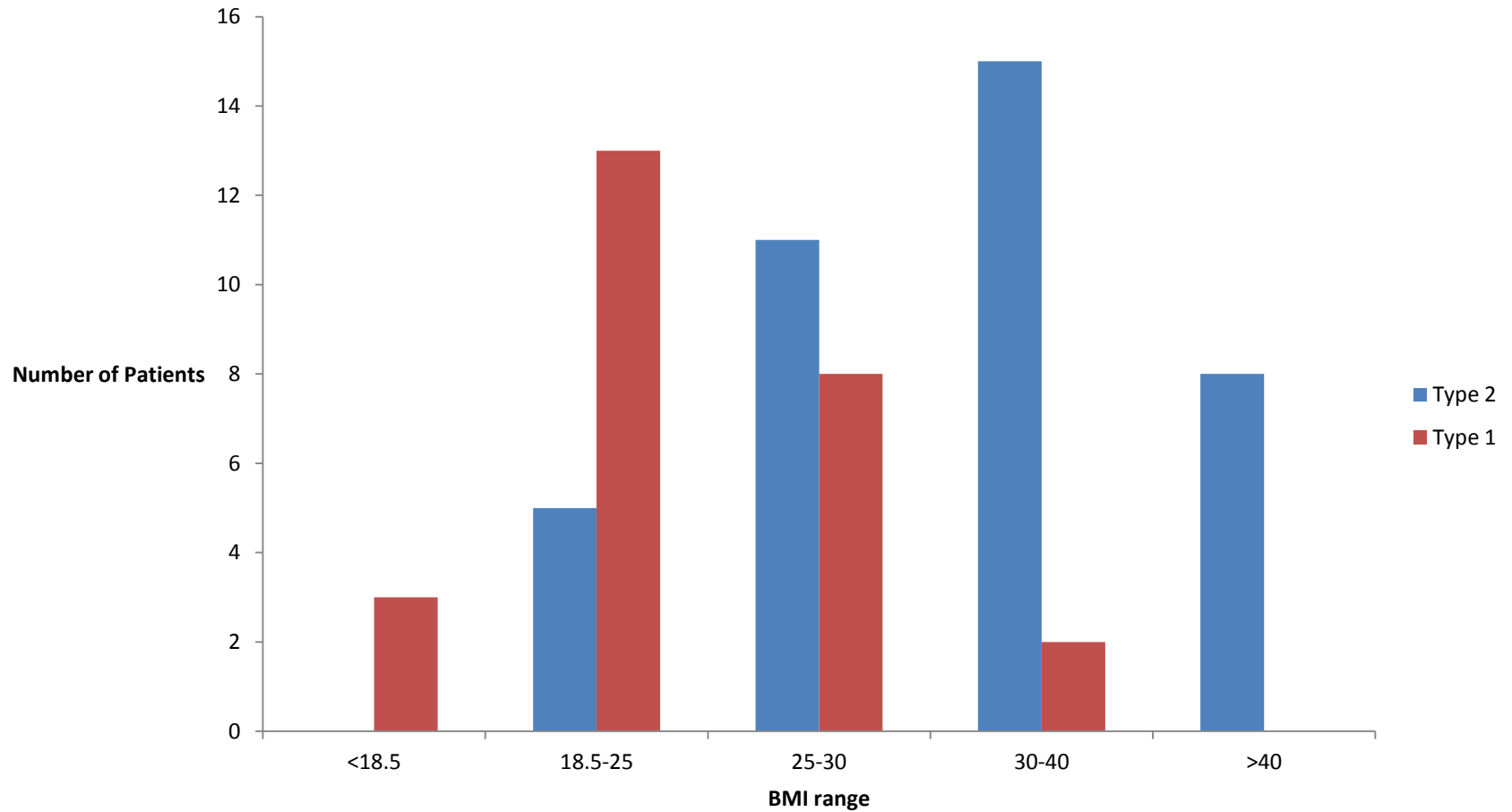
# Characteristics of Young People with Type 1 and Type 2 Diabetes in Newham

	Type 1	Type 2
Prevalence	2.16/1000	0.57/1000
Gender	52% Female	61% Female
Mean age of patients +Mean (SD)	20.2 (3.17)	21.2 (3.19)
Mean Age at time of diagnosis + Mean (SD)	10.6 (5.82)	15.2(3.34)
White ethnicity (%)	27.3%	13.6%
Mean BMI (kg/m <sup>2</sup> ) + Mean (SD)	24.2 (4.70)	33 (8.20)
Mean Total cholesterol (mmol/L) + Mean (SD)	4.6 (1.16)	6.5 (1.02)
Mean HbA1c (%) +Mean (SD)	10.0 (2.34)	8.4 (2.35)

# Distribution of Ethnicity Amongst Young People with Type 1 and Type 2 Diabetes in the group analysed



# BMI values for Young People with Type 1 and Type 2 Diabetes



# Young Adult Clinics – National Guidance and Models

- Transition not transfer
- Flexibility – Age (>16 years – 19/20/25 years)  
Appointments
- Multi-disciplinary (one-stop clinics)
- Most professionals feel they do not do well enough
- Most patients report the interaction with professionals is more important than the model



# Our Young Adult Service

- Joint monthly multi-disciplinary transitional clinic with the paediatric team
- Retinal screening and near patient testing (Hba1c) on-site
- Located in a “new” community health centre
- Designated diabetes specialist nurse – routine walk-in service, open access to specialist nurse, evening clinics
- Information leaflets (*What to expect from a consultation*)
- Text messaging reminders, email & telephone access
- Online discussion forum (in progress)



# Challenges

- DNA rates (2008/9): 37-50%
- Frequent A&E use by the same group of patients
- Poor self-management and engagement (LBN MORI 2009)
- Poor pregnancy planning
- Poor transition
- Poor clinical outcomes



# You're Welcome 2009/2010

- One of 14 National Pilot Sites
- Key Findings from three focus groups:
  - Need for improved ease and flexibility of access to acute services
  - Need for peer support groups
  - Need for a more “ holistic” model of care
- November 2010: Multi-agency stakeholder workshop (patients, carers, local colleges, commissioners, public health, police!) to develop a five-year plan for local Young People's Diabetes Services

# Access and Appointments

*“I can’t actually miss a lesson because its one of my crucial ones, and I have had to move it, once or maybe twice and because the dates are so long, it just gets a bit confusing because I did not know what dates were which and I’ve got all my appointment letters in my fridge or in a cupboard, so it does get bit confusing sometimes”*

# Internet Broadband Usage in Newham 2008-2009

Age	Broadband usage
16-24	86%
25-34	83%
35-44	73%
45-54	66%
55-64	63%
64+	21%

Above figures obtained from LBN  
National Average - ONS 2009 63% have internet  
broadband

Unweighted base

Base

Broadband internet at home via a high speed, always on connection

Wireless internet via laptop

Internet at work/place of study

Internet on a mobile phone

Internet at home via a 'dial up' modem

Internet at an internet cafes

Library

Via Games console e.g PS3/Wii

Via iPod

Dongle/webstick

Other

I do not use the Internet

DK/NA

ETHNICITY		
WHITE (t)	BLACK (u)	ASIAN (v)
350	187	416
320	240	390
206 65%	163 68%	290 74%
114 36%	86 36%	195 50%
109 34%	105 44%	168 43%
56 17%	48 20%	122 31%
25 8%	23 10%	38 10%
18 6%	23 10%	33 8%
1 *	1 1%	2 *
1 *	3 1%	1 *
1 *	1 *	1 *
3 1%	-	-
-	-	2 *
92 29%	55 23%	63 16%
-	1 1%	3
-	-	1 1%

# NHS Choices Pilot

Small proof of concept study February 2010:

15 patients

Established Type 1 and 2 diabetes

Age 18-25 years, both sexes

Range of ethnicity and self management skills

2 consultations per patient via Adobe Connect

Followed by online survey for all patients, and

telephone interviews of staff and patients, over 3 months

# Findings

Very popular with staff and patients

## ***Patient comments:***

- Convenient: not having to take time off work/school
- Did not need others eg. parents to take them for appointments
- Liked being in the comfort of home/privacy
- Felt health professional was giving them undivided attention and preferred this to telephone consultations
- Reduction in carbon footprint!



*“It is the same as with friends - although you can speak to them on Facebook, you still need to see them face to face sometimes for the relationship to work.”*

# DAWN – Diabetes Appointments via Webcam in Newham



*Care from home –  
Logo designed by  
Karen O’Leary,  
Service User*

*J Morris, T O’Shea, S Maddin, S Patel, M W Gill, S Vijayaraghavan*

**Partners:** NHS Choices, Newham Community and Health Care Services / EFLT, Newham GP Commissioning, NE London Sector and Acute Commissioning Unit

**Recognised by an award from:**



**Funded by:**

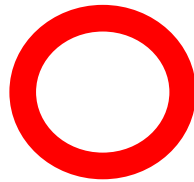


# DAWN - Diabetes Appointments via Webcam in Newham

## Aim:

Learn IF and HOW web-based consultations can provide more accessible and cost-effective care in the diabetes department; using readily available, affordable technology

## Webcam

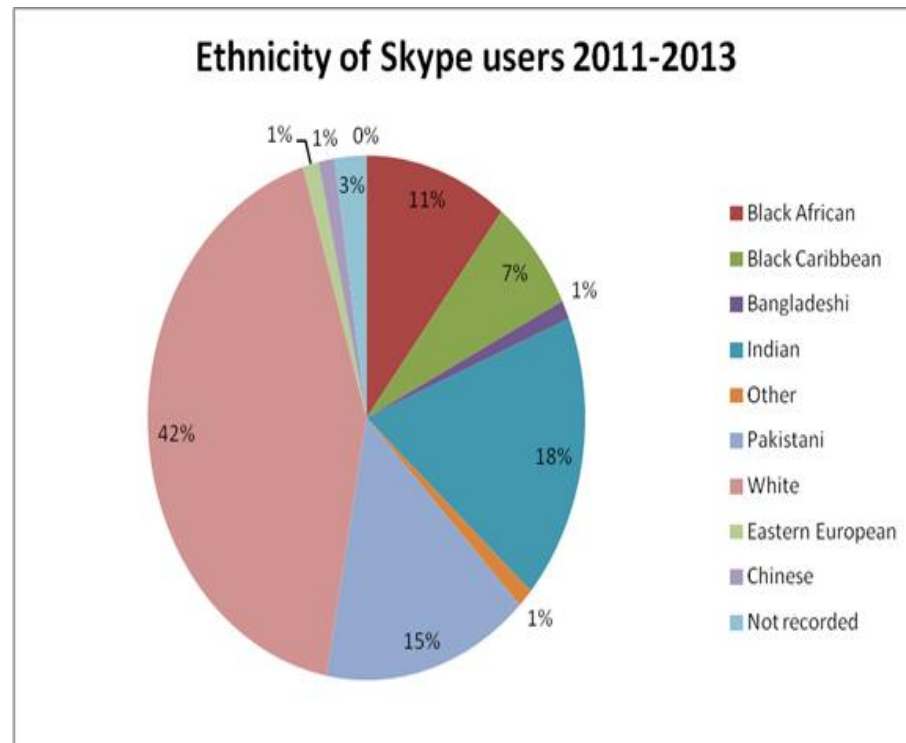


## Scope:

- Offer online consultations to all patients, where clinically appropriate and where examination not required, under care of one consultant and one nurse specialist (from May 11), within the existing clinic
- Include all ages
- Evaluate using quantitative and qualitative methods

# DAWN: Outcome data

Patient ages	% agreed
Under 50	82%
50 - 59	64%
60 - 69	29%
70 - 79	11%
Total	62%



# DAWN: Key Learning

1. Choice of software provider is important - ease of use and reliability of system matters

## Clinic 'do not attend' rates for webcam appointments

	Number of webcam appointments	Number of DNAs ('do not attends')	DNA rates
Overall	168 (68 patients)	46	27%
Software provider 1	137	41	30%
Software provider 2 (Skype)	31	5	16%

2. Transition time as patients move to a new model of care
3. A flexible approach – online care on video phones/ ad hoc appointments coupled with face-face contact works best

# DREAMS: Diabetes Review, Engagement And Management via Skype

Aim:

1. Explore the role of web-consultations in improving patient self-management
2. Specifically target “hard to reach” patients 16-25 years
3. Develop an “open access” virtual model
4. Test an online patient discussion forum for young people

# Outcome Measures – early data

- Two years on: 331 appointments; from 87 patients
- **DNA data:**  
Overall DNA rate 13% for scheduled appointments  
*(baseline DNA rates, same patients, 25%)*
- **Clinical outcomes measures, initial promising results**  
Of the patients who had >2 webcam appointments, the average Hba1c reduction was 1.65% (DCCT Values) ?  
suggesting greater compliance with medication and self-management

# DREAMS: Patient Feedback

## ACCESS

*“Skype is ‘great for diabetes’. Previously it meant taking a day off university to come to clinic.”*

## POSITIVE SHIFT IN DYNAMICS

*“I don’t think the consultant or the nurses actually realise, their whole attitude changes when they are in the consultation clinic, they have got the papers in front of them, they are fiddling with that, they are reading through it, but when they are on Skype they just look straight at you and they talk at you”*

## OWNERSHIP

*“Skype has helped to change my mind set in terms of management. There’s no excuse for missing appointments now”*

## LESS ANXIETY

*“I feel better controlled since using Skype and less anxious”*



*“Understand that there may be other things going on in my life when you treat me: be interested in me as a person, not just a diabetic”*

# Peer support for young people (16-25 years) with diabetes – impact on self-management and user engagement

**Aim:** a one-year project to explore the scope and feasibility of a peer-supported diabetes self-management programme for young people, using a “story sharing” model

- Monthly, evening drop-in two hour groups
- Community venues
- Ability to discuss a range of health/non-health issues
- Work with a range of local partners
- Facilitated by a social anthropologist and research nurse
- Involve young people in the design of these groups



# Bowling at Westfield – Building Peer Groups

# Key Learning

- Need Shared interests : ? 16- 25 years too wide an age range
- Patient Champions
- Need to work with a range of partners – local authority, social care, sixth form colleges, employers etc.
- No single point of contact



# Challenges

- Relationships – partners and patients
- IT and Data
- Tariff/funding/commissioning
- Patient Champions
- Organisational impact

# You're Welcome 2009/2010

- One of 14 National Pilot Sites
- Key Findings from three focus groups:
  - Need for improved ease and flexibility of access to acute services
  - Need for peer support groups
  - Need for a more “ holistic” model of care
- November 2010: Multi-agency stakeholder workshop (patients, carers, local colleges, commissioners, public health, police!) to develop a five-year plan for local Young People's Diabetes Services

# What next?

- VOCAL : Virtual Online Consultations – Advantages and Limitations, NIHR HS & DR, January 2015
- Working across organisational boundaries: ‘Is this the work of a specialist team?’
- Creating a Young People Hub







# Thank You

## **The team:**

*Teresa O'Shea, Diabetes Specialist Nurse*

*Ohmar Myint, Associate Specialist*

*Diana Markham, Specialist Dietitian*

*Abdul Moodambail, Consultant*

*Paediatrician*

*Jenny Hurley, PDSN*

*Rita Sudra, Diabetes Research Nurse*

*Desiree Campbell-Richards, Diabetes  
Research Nurse*

*Joe Wherton, Research Fellow*

*Joanne Morris, Research Manager*