HEALTH EQUITY: REASONABLE ADJUSTMENTS FOR PERSONS WITH A LEARNING DISABILITY IN DIABETIC EYE SCREENING PROGRAMME

NEC

NEC Care

Miu Chi TANG, Improving Screening Uptake Officer, Central Merseyside DESP (NEC CARE)

KEY ISSUE

There is no standard operating procedure to update records of persons with a learning disability in the Diabetic Eye Screening Programme (DESP). In the Optomize software there are only a few sites which are coded as "Learning Disabilities". Without sufficient information, it's difficult for the DESP to arrange reasonable adjustments for this group of people when necessary.

DEFINITION

By the NHS definition, a learning disability affects the way a person learns new things throughout their life. They might have some difficulty in understanding complicated information, learning some skills as well as looking after themselves or living alone. A learning disability is different for everyone. No two people are the same. (source: https://www.nhs.uk/conditions/learning-disabilities/)

CURRENT SITUATION

In the Central Merseyside DESP, the programme size is over 49,000 service users. Before starting this project, we could only find 18 active service user records that are coded as "Learning Disabilities". The related data will only be available through the GP2DRS or individual GPs upon request. There is no automated process to update the relevant patient information. Also, there is no standard operating process to review individual cases for any reasonable adjustments.

PROCEDURAL ADAPTATION IN DESP

With reference to the NHS England (North West)'s report titled "Improving awareness, access and uptake to Section 7a Screening and Immunisation Programmes for individuals with a learning disability", this two-year programme of work rolled out four high-impact interventions to improve awareness and access to breast and cervical screening for individuals who have a learning disability. The high-level process "Pilot 3: Pre-appointment call or triage" can also be applied to the DESP. This poster presents the findings from our Pilot study in which the high-level process as shown below has been applied.
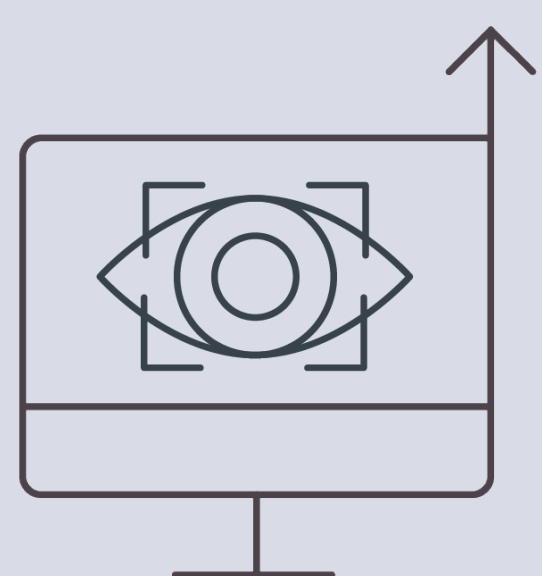
High-Level Operating Procedure to Identify Individuals with a Learning Disability

DATA
Engagement with Primary Care

ARRANGE
Scheduling or Reasonable Adjustments

DELIVERY
Prepare for Appointments

REVIEW & SHARE
On-going Review and Share the Best Practices

PILOT STUDY METHODOLOGY

DATA

- With the help of West Knowsley Primary Care Network, "Learning Disability & Diabetes Over 12 years for Retinopathy Screening" data from 4 general practices in Knowsley were received.
- 42 persons with diabetes coded as having "Learning Disabilities" plus a Learning Disability level label plus notes from GPs and carers' contact details in Optomize.

FINDINGS

Among 42 persons, here is the status of their pathway:

- 9 Past screening was successful
- 6 had been medically excluded due to unfit for screening
- 3 are waiting for confirmation of Medically Exclusion by GPs
- 1 postponed appointment
- 1 is currently under care of HES
- 12 were being contacted successfully to understand the needs of service users (literacy level / open eyes for drops / hold head or sit straight for camera) [see figure 1]
- 10 unreachable after two attempts of calling

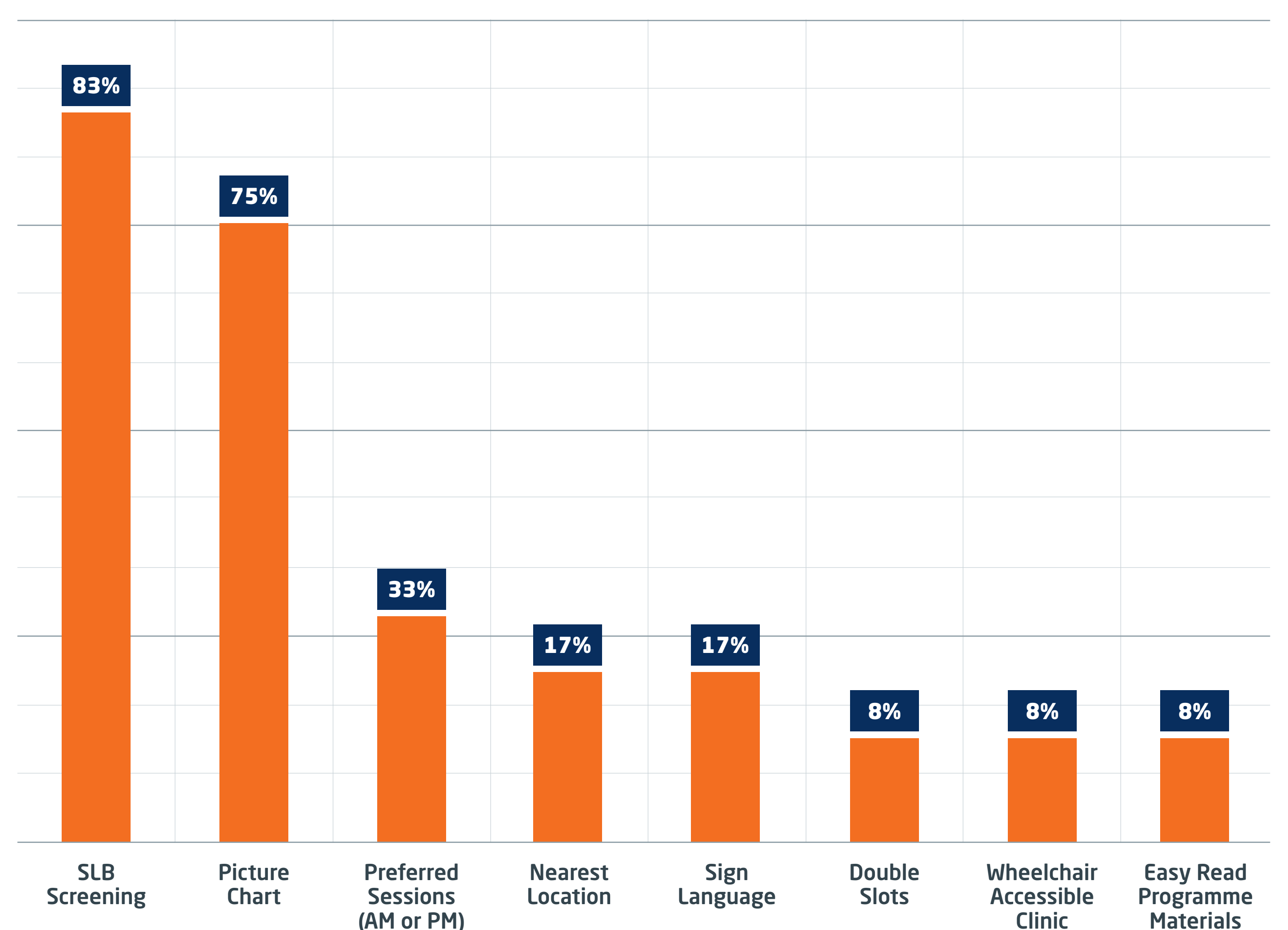### Adjustments Considered for Individuals with a Learning Disability

Figure 1: The most common reasonable adjustments for persons with a learning disability were considered to be: referral for Slit-Lamp Biomicroscopy (SLB) screening (83%) and the use of a picture chart (75%).

DELIVERY - CASE STUDY

- A 74 year old lady coded as severe learning disability. A week before the appointment, her carer was contacted to understand her needs. As the patient's literacy level is low, the use of picture chart was recommended.
- Screener was notified of the patient's request and prepared the picture chart in clinic.
- On the appointment day, the patient attended the appointment with her carer. The screener used a picture chart to test the patient's vision. The whole screening process was smooth.

REVIEW & SHARING OF INFORMATION

- The screener commented that the use of picture chart was very useful and a more accurate vision recording was obtained.
- SMS message was sent to invite patient's carer to share any comments.
- Follow up email was sent to the screener to share any comments or improvement ideas.
- The Pilot study findings were also shared at a Multi-Disciplinary-Meeting (MDT) and the Knowsley Learning Disability Health Forum.

SUGGESTIONS

Based on this Pilot study, the following are suggestions for improving user experience for persons with a learning disability:

1. GP healthcare workers to be trained to **code patients** with a learning disability correctly and promptly.
2. Learning Disability data should be able to be **downloaded** from the GP2DRS and **automatically transferred** to the Optomize on a monthly basis.
3. DESP staff members to to become familiar with **standing operating procedures (SOP)**, and to be able to decide the best adjustment for the person concerned and its delivery.
4. Develop and make available **easy read materials** including both online and offline.
5. Quick win: **Picture chart** to be prepared for every clinic and screeners to be trained to use the picture chart. SLB Clinics will be in a higher priority.

CONCLUSION

According to the SHAPE data from the Department of Health and Social Care, there are **4,278** service users registered as a learning disability in Central Merseyside. It is estimated that at least 10% of the population with diabetes have a Learning Disability. Therefore, at least **400** people with diabetes and Learning Disability can be found in the Central Merseyside DESP.

It may take some effort initially to implement this improvement plan. However, with a standard operating process to regularly review and follow up Learning Disability data in the DESP, it will be beneficial to all stakeholders. With reasonable adjustments to the screening process for those with a learning disability we anticipate that there will be less chance of DNAs or the need for re-appointment with an overall improvement in the uptake rate. The findings of the Pilot study will be shared with DESPs in other areas.