



**Sussex Partnership**  
NHS Foundation Trust

# Forget-Me-Not PPI with People with Dementia

Julia Fountain with Eddie and Mary Woods

# Time for Dementia (TfD)

- ❖ A novel educational programme for future health professionals to learn about dementia
- ❖ Pairs of students visit family in their own home 3 times per year for 2 years
- ❖ Aims to improve knowledge, attitudes and empathy towards people with dementia

# The INDEED Study (Dr Sam Robertson & Dr Stephanie Daley)



- ❖ Aim 1: To understand the experiences of people with dementia in the TfD programme.
- ❖ Aim 2: To explore more effective ways of capturing the experiences of people with dementia in research studies
- ❖ The student visits will be filmed and Sam will visit the person with dementia using the film as a prompt to help the person with dementia recall and describe their experience of the visit

# PPI in the INDEED Study

- ❖ We wanted to make sure that people living with dementia were involved to guide and advise us in every stage of the study
- ❖ But how can we meaningfully work with people with dementia without putting too high a burden on them?
- ❖ This is where Eddie and Mary come in





# Eddy and Mary and their groups



- ❖ Eddie's group for people with memory problems / dementia - Forget-Me-Not
- ❖ Mary's group for carers of people with dementia

# Julia visiting the Group

- ❖ The Forget-Me-Not group were keen to be involved but were clear on some ground rules
- ❖ We agreed that I will attend the group and start with a coffee. I briefly explain the study and our role and then ask the group 2-3 specific questions



# Julia visiting the Group

- ❖ The group members were clear that the mainly attend the group for companionship and fun
- ❖ So far, the visits have worked well with the group members saying they are enjoying the involvement and the study receiving useful advice

