



Oh the places Jo could go

Meredith Burke
 Mover and shaker in the Newcastle stroke scene
 Consumer Rep, Steering Committee
 Stroke Research Register – Hunter (Uni Newcastle)

 @merry_burke

Gillian Mason
 Person with lots of time-consuming health appointments
 Manager | Stroke Research Register – Hunter (Uni Newcastle)
 Communicator | NHMRC CRE Stroke Rehab & Brain Repair
 Clinical Research Assistant (Physio) | Centre for Rehab Innovations

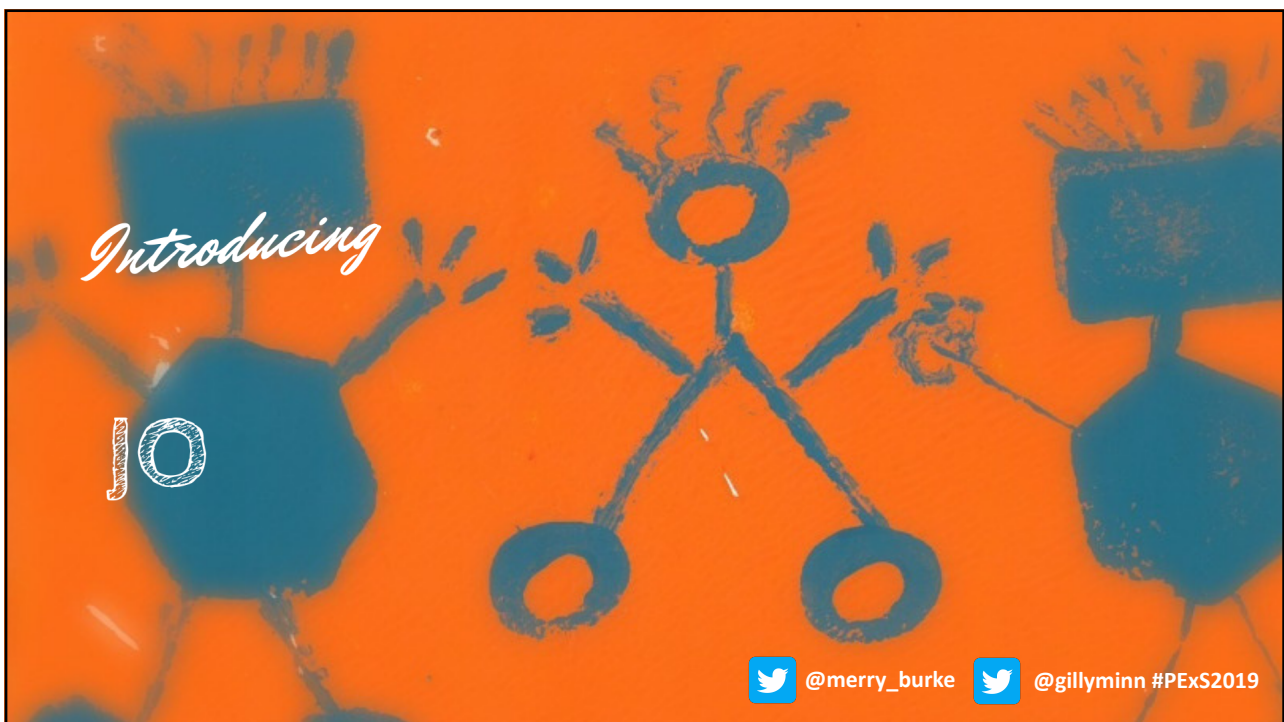
 @gillyminn









#PEXS2019

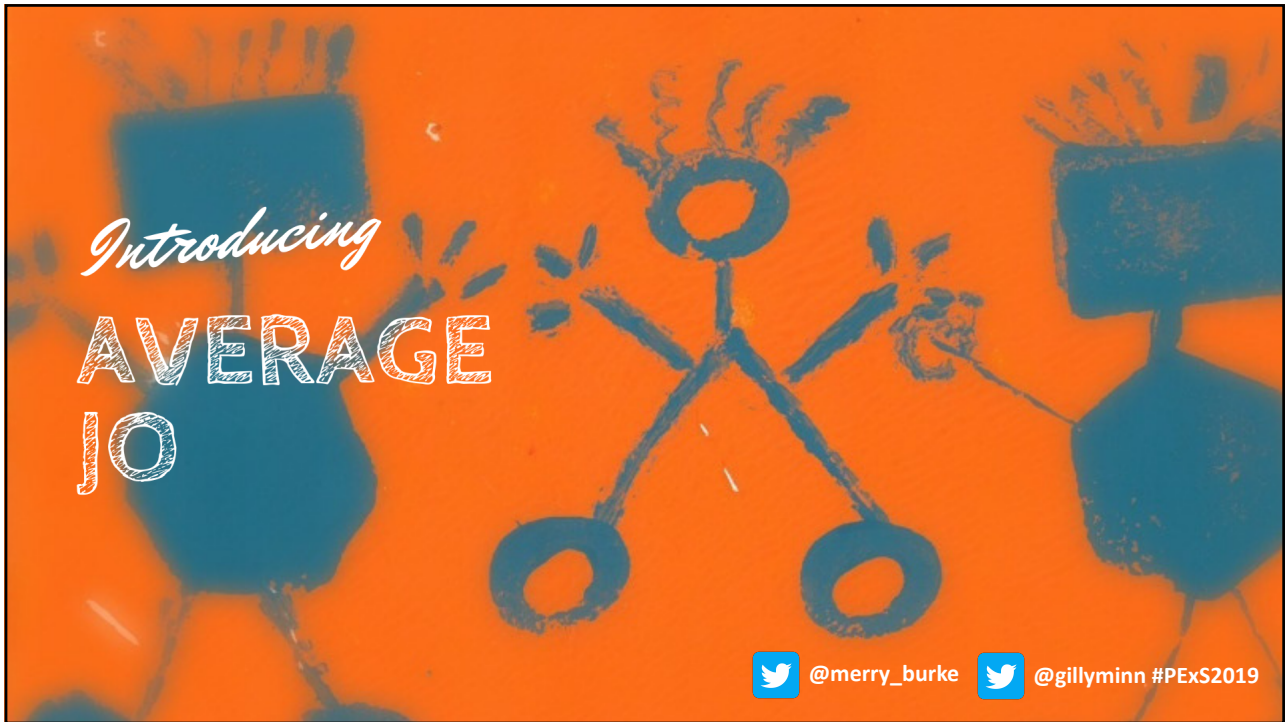


Introducing

Jo


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Start Date: 04 Apr 2012 09:20 End Date: 04 Apr 2012 16:00

Facility/Unit: John Hunter Hospital/JHH Emergency Room 04

Consultant/Specialty: MEDICINE, Dr Emergency IED

Triage nurse notes:

- Pt self presents states feels like has lost coordination
- since exercising this AM.
- Pt states sudden onset of headache behind eyes that resolved within minutes. Has since felt weak and uncoordinated.
- Pt hasnt ate today.

O/E well perfused, anxious lady, able to mobilise independently slowly.

GCS 15, PEARL size 4.

Equal strength in all limbs.

Denies pain at triage.

HR 87, ozsats 1005ra. BSL 4.3. Hx endometriosis.

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A 3D rendering of a white figure and an orange figure interacting with a white rectangular block. The white figure is on top of the block, leaning over it, while the orange figure is below the block, reaching up towards it.

Activity:

Assume
this
position

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Assumptions



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HMRI



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Communication Activity:

Draw what you hear



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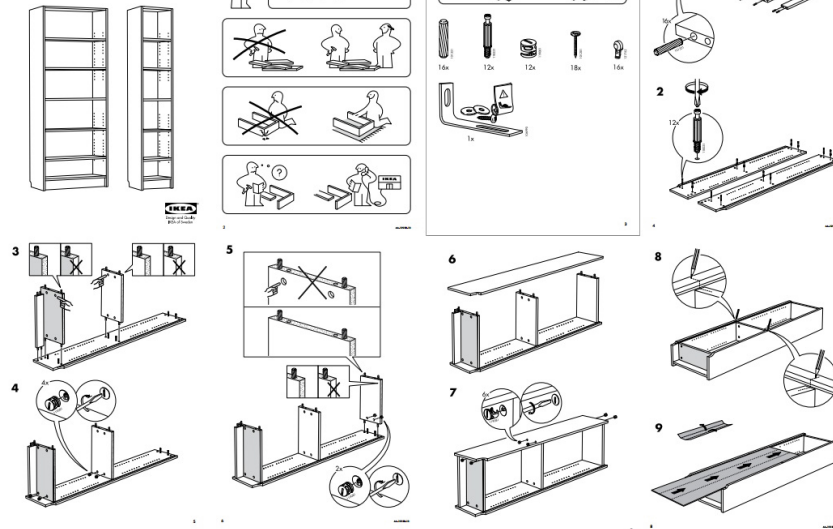


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Who do you work for?



BILLY



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  @gillyminn #PEXS2019

Communication Activity:

Read your appointment letter and explain to your partner what you need to do on 16th September 2019.

This is to confirm that you have an outpatient appointment in the JHH Infusion Clinic.

Your appointment is on Monday 16th September 2019 at 07:15

Your appointment is at the **Infusion Lounge in the Royal Newcastle Centre, next to the John Hunter Hospital**.

You will be required to:

- ❑ Arrive 5 minutes prior to your allocated appointment time in the North Block clinic area.
- ❑ If you are running late for your appointment you need to ring the Infusion Lounge as soon as possible and advise the ward clerk that this is the case. Infusions are scheduled to follow one after the other, therefore a late infusion will impact on the next scheduled patient for the clinic chair, and in some cases may need to be rescheduled to another day. Please give as much notice as possible if you cannot attend this appointment. The Infusion Lounge contact phone number is (02) 49 223473.
- ❑ When you arrive please wait in the North Block Medical Outpatients Waiting Area, you will need to present to the North Block main desk. Infusion Lounge staff will call you at your allocated appointment time, however, if you have not been called within 15-30 minutes please advise the Infusion Lounge clerical staff that you have arrived. We ask that you enter the Infusion Lounge via the hallway from the waiting area.
- ❑ Please minimise the number of people that accompany you. Your visitors will not be able to sit next to you during the infusion.
- ❑ To avoid delays in conducting infusions, and problems when medications are not in the Infusion Lounge when needed, we have revised the process for Infusion Lounge patients who collect their intravenous medication from DOCS Pharmacy at the Royal Newcastle Centre. **It is your responsibility and not that of the Infusion Lounge staff to ensure that the DOCS Pharmacy have your current prescription and are aware of the dates you will be requiring your infusions. Please note:** This is not applicable to patients receiving immunoglobulin (Ivlg).

You will be asked to quote your Medical Record Number (MRN) . We also need to know if any of your personal details, e.g. your name, address, telephone etc. have recently changed. This appointment time is made in good faith, but there may be long delays. **Smoking is not permitted in any Hunter New England Health buildings, grounds, car parks or vehicles.**

Note: Timed parking applies on this campus – less than 20 minutes is free, ranging from \$2.00 for 20 minutes to one hour, up to \$10.00 for more than 6 hours. Concession & disabled rates apply.

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Value of the patient

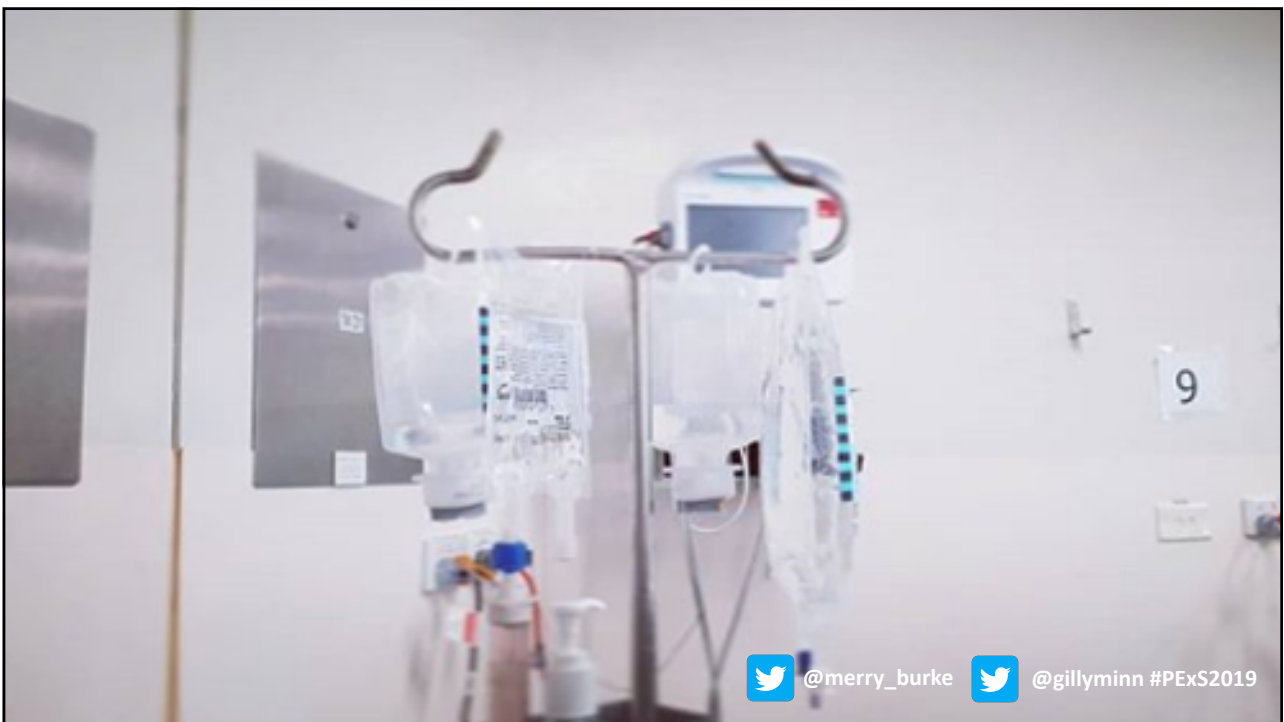
- Who is the communication for?
- Is it patient-centred, or process-centred?
- When you become a patient, do you still maintain your other life roles?



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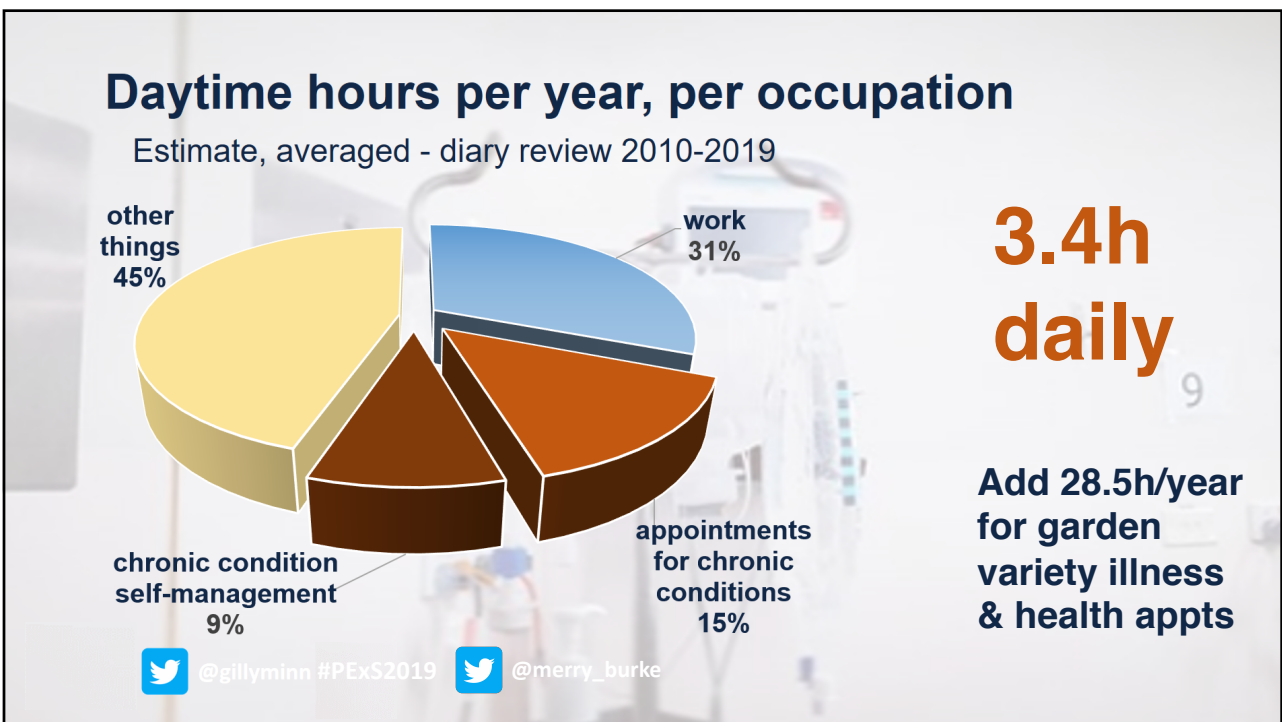
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Time spent on health related activities associated with chronic illness

- People w/ chronic illness & carers about 2h each daily
- Diabetes self-management > 2h extra daily. More time needed for elderly, newly diagnosed disease, physical limitations

Jowsey, T., Yen, L., & Mathews, P. (2012). Time spent on health related activities associated with chronic illness: a scoping literature review. *BMC Public Health*, 12:1044. [doi:10.1186/1471-2458-12-1044](https://doi.org/10.1186/1471-2458-12-1044)

Jeon, Y.H., Jowsey, T., Yen, L., Glasgow, N.J., Essue, B., Kljakovic, M.,.....Aspin C. (2010). Achieving a balanced life in the face of chronic illness. *Aust J Prim Health*, 16(1), 66-74.

Russell, L.B., Suh, D.C., Safford, M.A. (2005). Time requirements for diabetes self-management: too much for many? *J Fam Pract*, 54(1), 52-6.



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Getting the most out of research participants

- Who is the communication for?
- Is it person-centred, or process-centred?
- When you become a research participant, do you still maintain your other life roles?



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STROKE RESEARCH REGISTER HUNTER

You are invited to join the [Stroke Research Register - Hunter](#)

- a list of people with stroke or transient ischaemic attack (TIA)
- who are willing to take part in research studies



Where is the register?

At [Hunter Medical Research Institute](#)

- You may be invited to participate in different research studies
- Located across the Hunter region
 - Hunter Medical Research Institute
 - or
 - Newcastle University
 - or
 - Hospitals or community health centres (HNEHealth)
 - or
 - In the community or at home

What choices do you have?

1. Joining is voluntary
2. You choose which studies you want to take part in
3. Your choice will not affect your medical treatment or your relationship with the staff who are caring for you.
4. You can withdraw at any time & you won't have to give a reason.



Stroke Research Register - Hunter [16/08/2019] Participant Information - accessible format

17/02/2019



INFORMATION FOR PARTICIPANTS

There are no known risks of being on the Stroke Register.

Benefits

- Hear about stroke research studies

No Costs

- Will not cost you anything.
- You will not be paid.



Project Leaders

These researchers oversee the Stroke Register



[A/Prof Coralie English](#)
Physiotherapist researcher
Uni of Newcastle



[Prof Rohan Walker](#)
Neuroscientist
Uni of Newcastle



[Meredith Burke](#)
Stroke Survivor consumer rep



[Prof Michael Nilsson](#)
Rehabilitation doctor / neuroscientist
Uni of Newcastle



[Gillian Mason](#)
Register Manager / Physiotherapist
Uni of Newcastle



[A/Prof Michael Pollack](#)
Rehabilitation doctor
Hunter New England Health



[Monique Hourn](#)
Manager Subacute Research
Hunter New England Health

Stroke Research Register - Hunter [16/08/2019] Participant Information - accessible format

17/02/2019

Communication Activity:

Write an appointment letter or Participant Information Statement that is person-centred, and have your partner read it then explain to you what they need to do.

Think about the #PatientExperience



What are you going to do differently for Jo?

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