

Health Maintenance Tool

for people with spinal cord injury –
A tool for consumers from consumers

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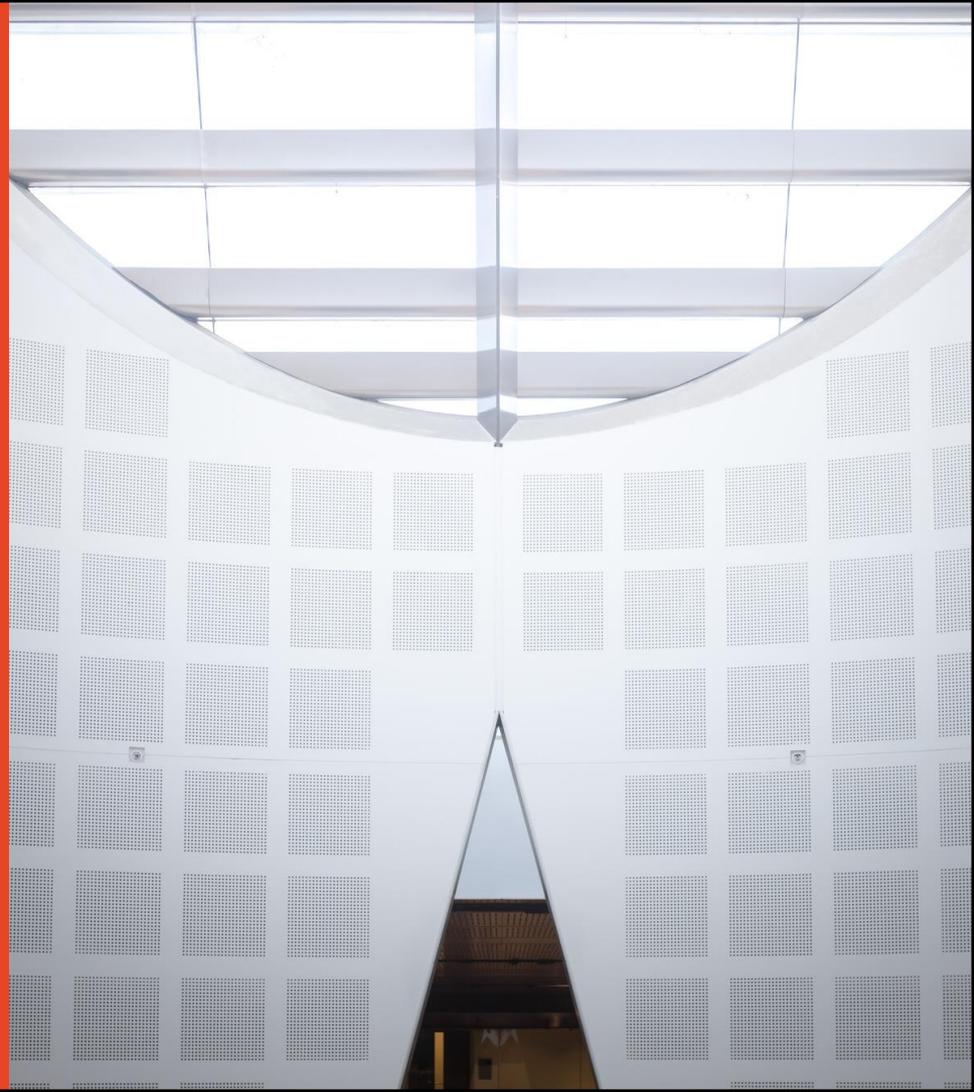
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DISCLOSURE STATEMENT

Authors' of this work declare no financial or competing interests in relation to this work.



RATIONALE



Lack of consumer friendly tools



Inconsistent information



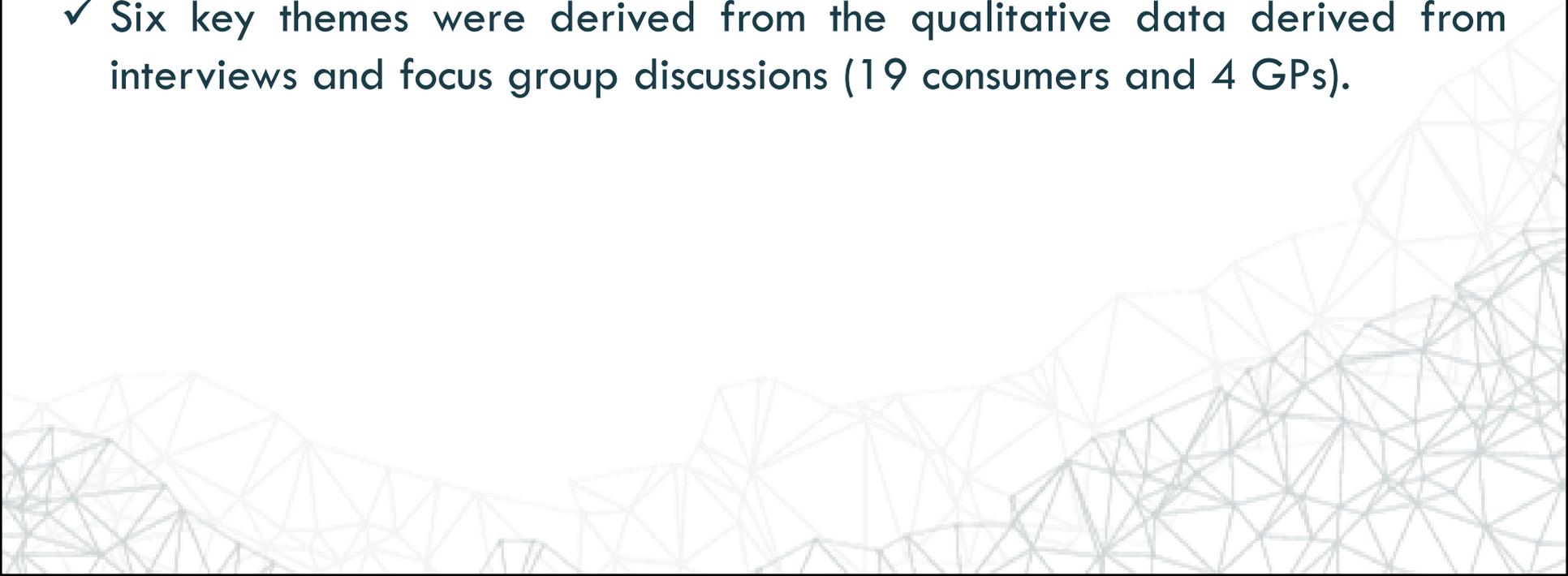
Community reintegration challenging



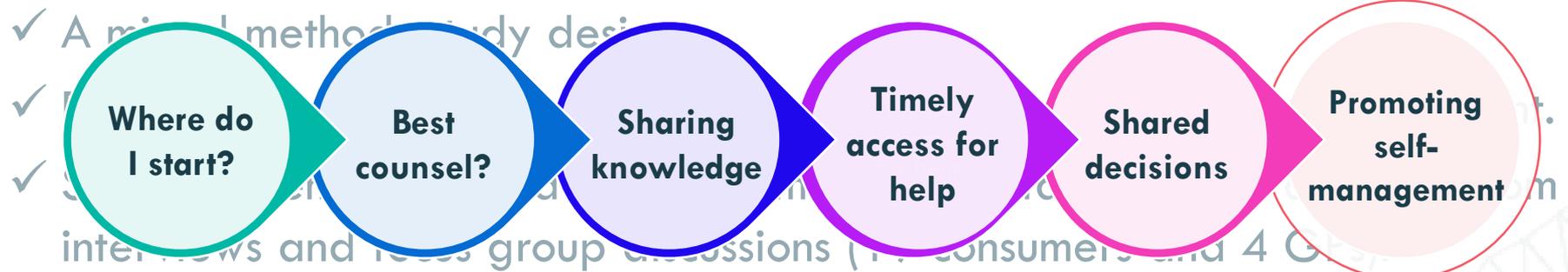
Increased risk of secondary conditions

Need for a health maintenance tool to inform and guide lifelong health promotion and early intervention to maintain consumer health, wellbeing and social participation

METHODS AND RESULTS

- ✓ A mixed methods study design.
 - ✓ Delphi survey for building consensus and to achieve complete agreement.
 - ✓ Six key themes were derived from the qualitative data derived from interviews and focus group discussions (19 consumers and 4 GPs).
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METHODS AND RESULTS



*I think knowledge is everything... having access to knowledge
(Consumer with SCI).*

*I suppose the question really here is how do we educate GPs
enough to have shared decision making, and how do we then use
that to develop more of a trust? (Consumer with SCI).*

*So for me I think it's really the long-term prognostic factors which
really motivate me into keeping healthy (Consumer with SCI).*



*I guess my approach to management is sort of personally is to do
no harm and to try to get them to be actively involved in general
well being as far as lifestyle choices (GP).*

*...so I think it needs to empower... the GP... gives the patient just as
much knowledge as they can about their condition, because then
they become more of a stakeholder I guess in the shared decision-
making (GP).*



Health Maintenance Tool

The HMT is a spinal-specific health maintenance schedule for five priority issues:



Bladder and its associated problems



Bowel and its associated problems



Skin and its associated problems



Pain



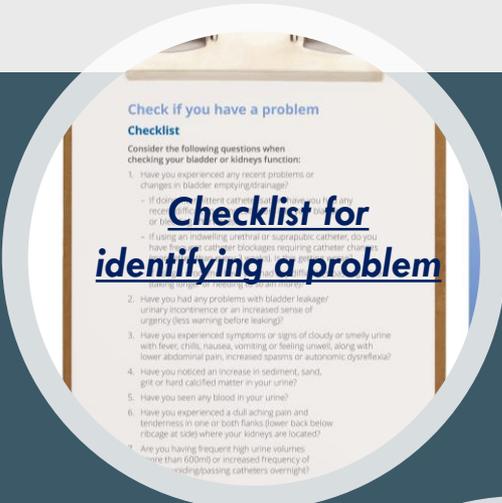
Autonomic dysreflexia



Health Maintenance Tool
How to stay healthy and well with a spinal cord injury
A tool for consumers from consumers

A product of the SCI Wellness Project
An initiative of Partnering with Funded by

Royal Rehab THE UNIVERSITY OF SYDNEY icare™
Empowering Independence *Insurance and Care NSW*



Health Maintenance Tool

It is a paper-based tool (pdf version), free to download, which is based on effective learning principles.

Practical solutions

Interactive elements

Screening tools

Easy-to-understand language

Use of illustrations

Highlighted key facts

Links to further reading

Easy-to-navigate sections



Tool navigator

Refer to the checklist and... (page 24)

PREVENT

Refer to: Self-management tips (page 20)

Urinary tract infection (page 21)

Bladder and kidney stones (page 22)

Routine follow-up and tests (page 23)

EDUCATE

Refer to: (page 24)

CHECK SEVERITY

Based on: Intensity/duration (page 25)

Limitation in functioning (page 26)

MANAGE

Based on problem severity and interference (page 33)

Self-manage without support

Self-manage with support from your GP or other healthcare professional

Manage with specialist support

Is this problem resolved? Have your goals been met?

Yes

What will happen if you do not manage your problem, say in time?

OBSERVE/PREVENT

Checklist for identifying a problem

Consider the following questions when checking your bladder or kidneys function:

- Have you experienced any recent problems or changes in bladder emptying/urine?
 - If you experience any of the following, do you need to see your GP or other healthcare professional?
 - If using an indwelling urethral or suprapubic catheter, do you have any blockage requiring catheter change?
 - Are you experiencing any of the following symptoms or signs of urinary tract infection?
- Have you had any problems with bladder leakage/urinary incontinence or an increased sense of urgency (less warning before leaking)?
- Have you experienced symptoms or signs of cloudy or smelly urine with fever, chills, nausea, vomiting or feeling unwell, along with lower abdominal pain, increased spasms or autonomic dysreflexia?
- Have you noticed an increase in sediment, sand, grit or hard calcified matter in your urine?
- Have you seen any blood in your urine?
- Have you experienced a dull aching pain and tenderness in one or both flanks (lower back below ribcage at side where your kidneys are located)?
- Are you having frequent high urine volumes (more than 600ml) or increased frequency of voiding/passing catheters overnight?

Problem	Interference rating	Management strategies
Severe problem	(3) Not at all	Self-manage
Mild problem	(1) A little of the time	Self-manage
Mild problem	(2) Some of the time	Self-manage with support from your GP or other healthcare professional
Moderate problem	(3) A lot of the time	Self-manage with support from your GP or other healthcare professional
Moderate problem	(3) Not at all	Self-manage with support from your GP or other healthcare professional
Moderate problem	(3) A lot of the time	Self-manage with support from your GP or other healthcare professional
Moderate problem	(3) A lot of the time	Manage with specialist support
Severe problem	(2) Some of the time	Manage with specialist support
Severe problem	(3) A lot of the time	Manage with specialist support

Note: If you are self-managing without support and your problem has not been resolved, you should seek help from your GP, another healthcare professional or involve a general cord injury specialist in your management plan.

Flowchart: Self-manage without support → Self-manage with support from your GP or other healthcare professional → Manage with specialist support

Manage "just-in-time"



Self-management tips



How to navigate this module

KNOW How your bladder and kidneys work (page 5)

CHECK Do you have a problem with your bladder or kidneys?
Refer to checklist and warning signs (page 13)

✓ Yes

IDENTIFY PROBLEM

Look for important signs and symptoms:

Urinary tract infection (page 19)
Catheter blockage (page 20)
Difficulty inserting an intermittent catheter (page 21)
Urine leakage (page 22)
Bladder and kidney stones (page 23)
Blood in urine (page 24)
Other problems (page 25-27)

CHECK SEVERITY

Based on the management index:

Severity scale (page 28)
Interference scale (page 29)

MANAGE

Based on problem severity and interference (page 28-29)

Self-manage without support

Self-manage with support from your GP or other healthcare professional

Manage with specialist support

Is this problem resolved? Have your goals been met?

✗ No

✓ Yes

RE-ASSESS

OBSERVE/PREVENT

✗ No

OBSERVE

Refer to questions in checklist and warning signs

PREVENT

Refer to:
Self-management tips (page 15)
Urinary tract infection (page 16)
Bladder and kidney stones (page 17)
Routine follow-up and tests (page 18)

EDUCATE

Refer to bladder management (page 19)

What will happen if you do not manage your problem 'just-in-time'? (page 30)

Take home messages

Check if you Understand Checklist

- Consider the following when checking your bladder and kidney health:
1. Have you experienced any changes in the way you urinate or feel when you urinate?
 2. Have you had any urinary tract infections (UTIs) or kidney stones?
 3. Have you experienced any urinary leakage or urgency (less than 15 minutes after you feel the need to urinate)?
 4. Have you noticed any blood in your urine?
 5. Have you noticed any changes in your urine colour or smell?
 6. Have you experienced any pain or discomfort when you urinate?
 7. Are you taking any medications that may affect your bladder or kidney health?

Identify



DEVELOP

a regular bowel routine and don't rush



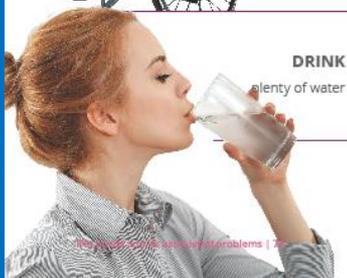
EAT

a balanced diet with enough fibre



MAINTAIN

a healthy lifestyle and exercise program



DRINK

plenty of water

TROUBLESHOOT

if you have a bowel problem



QUIT

smoking



AVOID

constipation



NEXT STEPS

The team at the University of Sydney is commencing the next phase in the project, involving:

- ✓ addition of a sixth module on Mental Health,
- ✓ pilot testing of the tool, and
- ✓ Web version of all six modules of the tool.



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THANK YOU!

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