



34067

Hospital ID: Site Staff ID: Participant ID: 

DRP: Diabetes Renal Project - (Patient Survey - Health Experiences)

Thank-you for participating in this large multi-centre research project, called the Diabetes Renal Project (DRP). This National Health and Medical Research Council (NHMRC) partnership project is being conducted by Monash University, in partnership with Monash Health, Alfred Health, Royal North Shore Hospital, Concord Repatriation General Hospital, The George Institute for Global Health, Diabetes Australia, and Kidney Health Australia.

INSTRUCTIONS

PLEASE:

Use a black **BIRO**, (DO NOT use a pencil or a fountain or felt tip pen)

Please **PRINT** in **CAPITAL** letters and stay within the box provided for text.

If you make a **mistake when writing**, cross it out with one thick line and write your correct answer above the box.

To answer a multiple choice question place a **CROSS INSIDE** the box like this:

If you make a **mistake**, place a diagonal line through the incorrect answer like this:

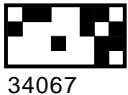
Write dates using leading zeros (e.g. **6th April 2011 = 06/04/2011**)

DO NOT USE liquid paper to correct mistakes.

AVOID folding the form.

Please complete every page of the questionnaire. Sometimes questions may seem very similar or repetitious but they are all a little different, so please answer each question.

THANK YOU



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Hospital ID:

Site Staff ID:

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Date

/ /

day / month / year

Part 1: Health Indicators (Patient Survey)

Section 1: General Information

1. Age (years)

2. Country of birth _____

3. Main language spoken at home?

- English
- Italian
- Spanish
- Greek
- Arabic
- Vietnamese
- Cantonese
- Hindi
- Mandarin
- Other, (please specify) → _____

Section 2: Diabetes

4. What type of diabetes do you have? Type 1 Type 2 Unsure Other

5. How many years have you had diabetes? years months

6. How do you manage your diabetes? (select all that apply)

- Diet and lifestyle only
- Insulin injections (3 or fewer per day)
- Tablets to lower blood glucose
- Insulin injections (4 or more per day)
- Byetta injections (2 per day)
- Insulin pump therapy
- Other (please specify) → _____

7. If you use insulin how confident are you in self- adjusting your insulin dose? (select one option)

Not at all confident 1 2 3 4 5 Extremely Confident

Section 3: Kidney Disease

8. How many years have you had kidney disease? years months

9. Did you develop kidney disease as a result of your diabetes? No Yes Unsure

Section 4: Medication

10. Who explains your medications to you? (select all that apply)

- GP
- Diabetes nurse
- GP Practice Nurse
- Kidney doctor at a public hospital clinic
- Private kidney specialist
- Diabetes doctor at a public hospital clinic
- Kidney nurse
- Pharmacist
- Private endocrinologist/diabetes specialist
- Other (please specify) → _____



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Hospital ID: Site Staff ID: Participant ID: **Section 4: Medication (cont)****11. Which health professional(s) do you see to manage your diabetes and kidney disease? (select all that apply)**

- GP Kidney doctor at a public hospital clinic
- GP Practice Nurse Diabetes doctor at a public hospital clinic
- Private kidney specialist Dietitian
- Kidney nurse Podiatrist
- Private endocrinologist/diabetes specialist Optometrist
- Diabetes nurse Ophthalmologist
- Other (please specify) → _____

12. Please record the last time you saw the following health professionals. (Select the appropriate frequency for each professional)

	0-3 months ago	4-6 months ago	7-12 months ago	Over 12 months ago	Never	Uncertain
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a. Endocrinologist (diabetes doctor)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Nephrologist (kidney doctor)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Diabetes Nurse Educator	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Kidney Nurse Practitioner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Optometrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Ophthalmologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Podiatrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Dentist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Dietitian	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Social Worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13. If you run out of medication what would you do? (Select all that apply)

- Obtain a supply from my local pharmacy, even if I didn't have a prescription
- Obtain a prescription from my GP then have it filled at my local pharmacy
- Wait until I next saw a doctor to obtain another prescription
- I never run out because I always ensure I have a spare supply



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Hospital ID: Site Staff ID: Participant ID: **Section 5. Barriers and support**

14. Barriers causing difficulty in caring for your diabetes and kidney disease (Mark disagree or somewhat disagree or somewhat agree or agree to each listed barrier. Please choose only one option per barrier).

	Disagree	Somewhat disagree	Somewhat agree	Agree
a. My diabetes and kidney specialist does not spend enough time with me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. My diabetes and kidney specialist does not provide me with enough information/education about my diabetes and kidney disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I am often seen by a different doctor each time I attend my diabetes or kidney disease appointment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. My specialists give me conflicting advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I do not have a good relationship with my specialist or other specialist health service staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Specialist health service staff are not caring, polite and helpful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. My specialists do not communicate well with my GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. My specialists don't communicate well with each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. I do not have a good GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. I need more education and understanding of my diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. I need more education and understanding of my kidney disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. The information provided by my doctors or health professionals is hard to understand because English is not my first language or the information is not culturally relevant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. The information provided by my doctors or health professionals is too complicated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. It is difficult to obtain medical support and advice for my diabetes when I need it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. It is difficult to obtain medical support and advice for my kidney disease when I need it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. I have had an unsatisfactory prior experience with a diabetes or kidney health service/specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q. I am unable to afford the cost of attending appointments or buying medication for my diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r. I have trouble adjusting to the impact that diabetes and kidney disease has made on my life and/or that of my family and friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s. My diabetes and kidney disease makes me feel very unwell	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t. My other illnesses affect my ability to look after my diabetes and kidney disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



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Hospital ID: Site Staff ID: Participant ID: **Section 5: Barriers and support (cont)**

	Disagree	Somewhat disagree	Somewhat agree	Agree
u. I have many other stressors in my life, and taking care of my diabetes and kidney disease is not a high priority	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
v. My job makes it difficult to take care of my diabetes and kidney disease well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
w. My mood (e.g. feeling down, worried, frustrated) gets in the way of me looking after my diabetes and kidney disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
x. I do not feel motivated enough to look after my diabetes and kidney disease well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
y. I have trouble maintaining the right diet or fluid restriction for my diabetes and kidney disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
z. I have difficulty knowing what I can eat/drink, for my diabetes and kidney disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
aa. I experience unpleasant side-effects from my medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
bb. I do not receive support from my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
cc. I do not receive support from my friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
dd. I find it difficult to get services for home-help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ee. Please list any additional problems:	<input type="text"/>			

Section 6: Diabetes Service and Kidney Service

15. Are you registered with the National Diabetes Service Scheme (NDSS)? *This service supports people living with diabetes by providing subsidised blood glucose strips and free insulin pen needles/syringes. It is not the same as being a member of Diabetes Australia.* No Yes

16. Do you have difficulty in accessing a diabetes service?

No → Skip to Q 17

Yes → **16.1. Why is it difficult for you to access a diabetes service?** (select all that apply)

No private transport e.g. car/ driver

Time spent each week at dialysis

Parking (e.g. cost, locality to the clinic)

I have too many appointments

Disability

Long waiting times before I get an appointment

Cost (e.g. appointments, prescription costs)

Long waiting times in the waiting room before I see a doctor

Time of appointment (e.g. during work hours)

I don't have a problem with accessing a service

Location of the service (e.g. distance from home)

Other (please specify) →



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Section 6: Diabetes Service and Kidney Service (cont)

17. How satisfied are you with the care provided by your diabetes service? (select one option)

Not at all satisfied [] 1 [] 2 [] 3 [] 4 [] 5 Extremely Satisfied

18. Do you have difficulty in accessing a kidney service?

[] No → Skip to Q 19

[] Yes → **18.1. Why is it difficult for you to access a kidney service? (select all that apply)**

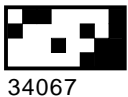
- No private transport e.g. car/ driver
- Parking (e.g. cost, locality to the clinic)
- Disability
- Cost (e.g. appointments, prescription costs)
- Time of appointment (e.g. during work hours)
- Location of the service (e.g. distance from home)
- Other (please specify) → _____
- Time spent each week at dialysis
- I have too many appointments
- Long waiting times before I get an appointment
- Long waiting times in the waiting room before I see a doctor
- I don't have a problem with accessing a service

19. How satisfied are you with the care provided by your kidney service? (select one option)

Not at all satisfied [] 1 [] 2 [] 3 [] 4 [] 5 Extremely Satisfied

20. An ideal health service to look after my diabetes and kidney disease would include: (please cross either no or yes in the table below)

- | | | |
|--|-----------------------------|------------------------------|
| a. Regular contact with a case manager, nurse or doctor who knows my entire medical history and who will help me coordinate the management of my health | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| b. Education sessions to help me manage my diabetes, including information about correct food choices and what support is available | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| c. Education sessions to help me manage my kidney disease, including information about correct food choices and what support is available | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| d. Education sessions for my family so that they can understand my condition | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| e. Education sessions targeted to the public/community about diabetes and kidney disease | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| f. Education handouts that are culturally relevant, in my native language, easy to understand, and in an appropriate format (e.g. DVD) | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| g. Seeing the same doctor or health professional when I attend my diabetes and kidney disease appointments | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| h. All my doctors giving me the same information/advice, instead of conflicting information/advice | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| i. Good communication between my doctors | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| j. Centralised Electronic health medical records with investigation results, which all my doctors can access | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| k. Friendly, caring, supportive and knowledgeable staff and medical professionals | <input type="checkbox"/> No | <input type="checkbox"/> Yes |



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Section 6: Diabetes Service and Kidney Service (cont)

l. A combined multidisciplinary clinic with both diabetes and kidney doctors, as well as other health staff (such as dietitian, nurse educators, podiatrists etc) in the one place No Yes

m. Shorter waiting times in the waiting room No Yes

n. Routine access to a psychologist for emotional support No Yes

o. Routine access to a dietitian No Yes

p. Routine access to a podiatrist No Yes

q. Routine access to an eye doctor No Yes

r. Routine access to a diabetes nurse educator No Yes

s. Routine access to a kidney nurse No Yes

t. Routine access to a pharmacist No Yes

u. Routine access to a social worker No Yes

v. Routine access to an occupational therapist No Yes

w. Routine review by doctors and health professionals for my diabetes and kidney disease (e.g. diabetes doctor, dietitian, podiatrist) while I am on dialysis No Yes

x. Appointment reminders (e.g. phone call/text message/email) prior to my appointment No Yes

y. Incentives to staff members to provide good patient service (e.g. Monthly prize) No Yes

z. Debriefing groups and education sessions for staff members to improve patient care No Yes

aa. Affordable parking close to clinic/dialysis No Yes

bb. Diabetes and renal services being offered in my local community, rather than primarily based in the hospital No Yes

cc. 24 hour hotline to staff in case I need advice or assistance No Yes

Section 7: Summary of Diabetes Self Care Activities for Diabetes and Kidney Disease

Please recall the last 7 days that you were well when answering the following questions. (Please select one response per question).

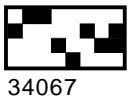
Diet

21. How many of the last 7 days have you followed a healthy eating plan?

0 1 2 3 4 5 6 7

22. Over the past month how many days per week have you followed your eating plan?

0 1 2 3 4 5 6 7



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Section 7: Summary of Diabetes Self Care Activities for Diabetes and Kidney Disease (cont)

23. On how many of the last 7 days did you eat five or more servings of fruit?

0 1 2 3 4 5 6 7

24. On how many of the last 7 days did you eat high fat foods such as red meat or full dairy products?

0 1 2 3 4 5 6 7

Exercise

25. On how many of the last 7 days did you participate in at least 30min of exercise?

0 1 2 3 4 5 6 7

26. On how many of the last 7 days did you participate in a specific exercise session?

0 1 2 3 4 5 6 7

Blood Sugar Testing

27. On how many of the last 7 days did you test your blood sugar?

0 1 2 3 4 5 6 7

28. On how many of the last 7 days did you test your blood sugar the number of times recommended by your health care provider?

0 1 2 3 4 5 6 7

Foot Care

29. On how many of the last 7 days did you check your feet?

0 1 2 3 4 5 6 7

30. On how many of the last 7 days did you inspect the inside of your shoes?

0 1 2 3 4 5 6 7

Smoking

31. Have you smoked or taken a puff of a cigarette in the last 7 days?

No → Skip to Q 32

Yes → **31.1 How many cigarettes did you smoke on an average day?** [][][]

Medications

32. On how many of the last 7 days did you take your recommended diabetes medication?

0 1 2 3 4 5 6 7

33. On how many of the last 7 days did you take your recommended insulin injections?

0 1 2 3 4 5 6 7

34. On how many of the last 7 days did you take your recommended number of diabetes pills?

0 1 2 3 4 5 6 7