

# Section 1

## Introduction and methods

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Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

This PEEK study in bladder cancer includes 44 people diagnosed with bladder cancer throughout Australia. In addition, 5 carers or family members to people with bladder cancer took part.

Bladder cancer occurs more frequently in men and those over 60 years of age. In 2021 there were an estimated 3,066 new cases of bladder cancer in Australia, approximately 2,400 of these were men; the median age was 76.3 years. There were an estimated 653 deaths from bladder cancer in Australia in 2021, it is the 9<sup>th</sup> most common cause of death from cancer<sup>2</sup>. The five year survival during the period 2011 to 2017 was 55%. In Australia, at the end of 2016, there were 8165 people living with bladder cancer.

There was a decrease in 5 year survival from 68% in 1982 – 1987, to 53% in 2009-2013, the reasons for this are not clear and cannot be explained by an increase in age at diagnosis which has only modestly increased in this time period<sup>1,4</sup>. However, there was a decrease in age-standardised mortality rate from 5.4 per 100,000 in 1982 to 3.8 per 100,000 in 2017, this is due to a reduction of overall incidence.

## **Introduction**

Bladder cancer occurs more frequently in men and those over 60 years of age<sup>1</sup>. In 2021 there were and estimated 3,066 new cases of bladder cancer in Australia, approximately 2,400 of these were men; the median age was 76.3 years<sup>2,3</sup>. There were an estimated 653 deaths from bladder cancer in Australia in 2021, it is the 9<sup>th</sup> most common cause of death from cancer<sup>2</sup>. The five year survival during the period 2011 to 2017 was 55%<sup>3</sup>. In Australia, at the end of 2016, there were 8165 people living with bladder cancer<sup>3</sup>.

There was a decrease in 5 year survival from 68% in 1982 – 1987, to 53% in 2009-2013, the reasons for this are not clear and cannot be explained by an increase in age at diagnosis which has only modestly increased in this time period<sup>1,4</sup>. However, there was a decrease in age-standardised mortality rate from 5.4 per 100,000 in 1982 to 3.8 per 100,000 in 2017<sup>1</sup>, this is due to a reduction of overall incidence.

### ***Personal Experience, Expectations and Knowledge (PEEK)***

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

The research protocol used in PEEK studies is independently driven by CCDR. PEEK studies include a quantitative and qualitative component. The quantitative component is based on a series of validated tools. The qualitative component is the result of two years of protocol testing by CCDR to develop a structured interview that solicits patient experience data and provides patients with the opportunity to provide advice on what they would like to see in relation to future treatment, information and care. The structured interview has also been designed so that the outcomes of PEEK studies can inform policy, research, care, information, supportive care services and advocacy efforts.

## ***Participants***

To be eligible for the study, participants needed to have been diagnosed with bladder cancer, have experienced the healthcare system in Australia, be 18 years of age or older, be able to speak English, and be able to give consent to participate in the study. Recruitment commenced 1 April 2022 and was completed by 30 July 2022.

### ***Ethics***

Ethics approval for this study was granted (as a low or negligible risk research study) by the Centre for Community-Driven Research Ethics Committee (Reference CS\_Q4\_03).

### ***Data collection***

Data for the online questionnaire was collected using Zoho Survey (Zoho Corporation Pvt. Ltd. Pleasanton, California, USA, [www.zoho.com/survey](http://www.zoho.com/survey)). Participants completed the survey from 1 April 2022 to 30 July 2022.

There were five researchers who conducted telephone interviews and used standardised prompts throughout the interview. The interviews were recorded and transcribed verbatim. Identifying names and locations were not included in the transcript. All transcripts were checked against the original recording for quality assurance.

Interview data was collected from 1 April 2022 to 30 July 2022.

### ***Online questionnaire (quantitative)***

The online questionnaire consisted of the 36-Item Short Form Health Survey (SF36) (RAND Health)<sup>5</sup>, a modified Cancer Care Coordination Questionnaire for Patients (CCCQ)<sup>6</sup>, the Short Fear of Progression Questionnaire (FOP12)<sup>7</sup>, and the Partners in Health version 2 (PIH)<sup>8</sup>. In addition, investigator derived questions about demographics, diagnosis, treatment received and future treatment decisions making were included.

### **Structured Interview (qualitative)**

Interviews were conducted via telephone by registered nurses who were trained in qualitative research. The first set of interview questions guided the patient through their whole experience from when symptoms were noticed up to the present day.

### **Questionnaire analysis**

Statistical analysis was conducted using R included in the packages “car”, “dplyr” and “ggplot2” (R 3.3.3 GUI 1.69 Mavericks build (7328)). The aim of the statistical analysis of the SF36, CCCQ, FOP12, and PIH responses was to identify variations by disease stage, gender, location of residence, education status and socio-economic status. Scales and subscales were calculated according to reported instructions<sup>5-8</sup>.

The Location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics<sup>9</sup>.

The level of socio-economic status of participants was evaluated by postcode using the Socio-economic Indexes for Areas (SEIFA) accessed from the Australian Bureau of Statistics<sup>10</sup>.

For comparisons by disease stage, a one-way analysis of variance (ANOVA) analysis was conducted. A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test. Where the assumptions for the one-way ANOVA were not met, a Kruskal-Wallis rank sum test on care was conducted with post-hoc pairwise comparisons using Wilcoxon rank sum test. When the assumption of equal variances were not met, a Welch one-way test was used with post-hoc pairwise t-tests with no assumption of equal variances.

For all other comparisons between groups, a two-sample t-test was used when assumptions for normality and variance were met, or when assumptions were not met, a Wilcoxon rank sum test with continuity correction was used. Questions where participants were asked to rank preferences were analysed using weighted averages. Weights were applied in reverse, the most preferred option was given the largest weight equal to the number of options, the least preferred option was given the lowest weight of 1.

### **Structured interviews analysis**

A content analysis was conducted using conventional analysis to identify major themes from structured interviews. Text from the interviews were read line-by-line by the lead researcher and then imported into NVivo 8 (QSR International)/MaxQDA. Each question within the interview was individually analysed. Initial categories and definitions were identified and registered in NVivo 8 (QSR International)/MaxQDA. The minimum coded unit was a sentence with paragraphs and phrases coded as a unit.

A second researcher verified the codes and definitions, and the text was coded until full agreement was reached using the process of consensual validation. Where a theme occurred less than 5 times it was not included in the study results, unless this result demonstrated a significant gap or unexpected result.

Data analysis and final reporting was completed in June 2021.

### **Position of this study**

A search was conducted in Pubmed (April 7, 2022) to identify studies of bladder cancer with patient reported outcomes, or patient experience conducted in the past five years in worldwide (Table 1.1). Meta-analysis studies, studies with children, studies conducted in developing countries, population studies, and studies of less than five participants were excluded. There were 99 studies identified of between 8 and 1796 liver cancer participants.

There were 10 studies that interviewed between 10 and 30 people with bladder cancer. There were 3 studies that were focused on treatment<sup>11-13</sup>, 2 studies that were focused on health related quality of life<sup>14,15</sup>, and a single study each focused on diagnosis<sup>16</sup>, education<sup>17</sup>, decision making<sup>18</sup>, healthcare services<sup>19</sup>

There were 7 studies where 10 to 57 people with bladder cancer took part in focus groups, two of these studies included interviews and are described above. There were 3 studies that were focused on healthcare service<sup>20-22</sup>, and a single study each focused on treatment<sup>23</sup>, and lifestyle<sup>24</sup>

There were 65 studies that were focused on treatment<sup>5,9,10,25-86</sup>, 6 studies that were focused on Health related quality of life<sup>87-89</sup>, 3 studies that were focused on Lifestyle<sup>90-92</sup>, 2 studies that were focused on diagnosis<sup>93,94</sup>, 2 studies that were focused on costs to patients<sup>95,96</sup>, 2 studies that were focused on complementary therapy<sup>97,98</sup>, and a single study each focused on healthcare services<sup>99</sup>, decision making<sup>100</sup>, and education<sup>101</sup>

In this PEEK study, 44 people with bladder cancer were interviewed and completed questionnaires, in addition to 5 carers of people with bladder cancer. PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

**Table 1.1: PEEK position**

First Author, Year	Location	Number of participants	Data collection	Focus	PEEK SECTION							
					2: Health status, co-morbidities	3: Diagnosis experience	4: Decision making	5: Treatment, healthcare system use	6: Information, communication and self-management	7: Care, support and navigating healthcare system	8: Quality of life, mental health, relationships	9: Expectations, preferences and messages
McMullen (2019) <sup>23</sup>	USA	57 (5 carers)	Focus group	Treatment			X	X	X			
Gupta (2021) <sup>13</sup>	USA	22 (3 partners)	Interviews/ focus groups	Treatment							X	
Rammant (2019) <sup>11</sup>	Belgium	30	Interview	Treatment	X	X		X			X	
Yi (2022) <sup>12</sup>	Korea	9	Interview	Treatment							X	
Garg (2018) <sup>20</sup>	USA	20	Focus group	Healthcare service			X	X		X	X	
Lee (2020) <sup>21</sup>	USA	19	Focus group	Healthcare service					X			
Koo (2017) <sup>22</sup>	USA	12	Focus group	Healthcare service			X	X			X	
Jordan (2022) <sup>19</sup>	USA	10	Interview/ focus group	Healthcare service			X		X	X		
Rutherford (2017) <sup>14</sup>	Australia	26	Interview	Health related quality of life	X	X						
Heyes (2020) <sup>15</sup>	Australia	8	Interview	Health related quality of life						X	X	
Tan (2020) <sup>102</sup>	UK	20 interview, 213 quest.	Interviews/ questionnaire	Diagnosis	X	X					X	
Schroek (2020) <sup>16</sup>	USA	22	Interview	Diagnosis					X			
Wulff-Burchfield (2021) <sup>17</sup>	USA	16	Interview	Education					X			
Banerjee (2021) <sup>24</sup>	UK	14	Focus group	Lifestyle				X			X	
Klein (2021) <sup>18</sup>	USA	13	Interview	Decision making			X					X
Witjes (2022) <sup>25</sup>	Multi-national	709	Questionnaire	Treatment	X	X						
Bajorin (2021) <sup>26</sup>	Multi-national	709	Questionnaire	Treatment	X	X						

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Kelly (2019) <sup>27</sup>	UK	709	Questionnaire	Treatment	X	X							
Mason (2018) <sup>28</sup>	England	673	Questionnaire	Treatment	X	X							
Necchi (2020) <sup>29</sup>	Multi-national	530	Questionnaire	Treatment	X	X							
Vaughn (2018) <sup>30</sup>	Multi-national	519	Questionnaire	Treatment	X	X							
Huddart (2020) <sup>31</sup>	UK	485	Questionnaire	Treatment	X	X							
Cox (2020) <sup>32</sup>	UK	472	Questionnaire	Treatment	X								
Clements (2022) <sup>33</sup>	USA	411	Questionnaire	Treatment	X	X							
Westhofen (2022) <sup>34</sup>	Germany	407	Questionnaire	Treatment	X	X							
Kukreja (2018) <sup>35</sup>	USA	383	Questionnaire	Treatment		X							
Masiero (2021) <sup>9</sup>	Italy	382	Questionnaire	Treatment	X	X							
Wijburg (2021) <sup>10</sup>	Netherlands	348	Questionnaire	Treatment	X								
Hupe (2018) <sup>36</sup>	Germany	324	Questionnaire	Treatment	x	x							
Cerruto (2017) <sup>37</sup>	Italy	319	Questionnaire	Treatment	X	X							
Becerra (2020) <sup>38</sup>	USA	302	Questionnaire	Treatment	X	X							
Frees (2017) <sup>39</sup>	Germany	250	Questionnaire	Treatment	X	X							
Volz (2022) <sup>40</sup>	Germany	246	Questionnaire	Treatment	X	X							
Asanad (2021) <sup>41</sup>	USA	198	Questionnaire	Treatment	X	X							
Check (2020) <sup>42</sup>	USA	192	Questionnaire	Treatment	X	X	X	X					
Grimm (2019) <sup>43</sup>	Germany	178	Questionnaire	Treatment	X	X							
Normann (2020) <sup>44</sup>	Norway	173	Questionnaire	Treatment	X	X							

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Kijima (2019) <sup>45</sup>	Japan	154	Questionnaire	Treatment	X	X							
Loh-Doyle (2020) <sup>46</sup>	USA	151	Questionnaire	Treatment		X							
Kern (2021) <sup>47</sup>	USA	146	Questionnaire	Treatment	X	X							
Siracusano (2018) <sup>48</sup>	Italy	145	Questionnaire	Treatment	X	X							
Rehme (2022) <sup>49</sup>	Germany	143	Questionnaire	Treatment	X								
Kretschmer (2020) <sup>50</sup>	Germany	134	Questionnaire	Treatment	X	X							
Westerman (2020) <sup>51</sup>	USA	132	Questionnaire	Treatment	X	X							
Gellhaus (2017) <sup>52</sup>	USA	128	Questionnaire	Treatment	X	X							
Mastroianni (2022) <sup>53</sup>	Italy	116	Questionnaire	Treatment	X								
Danielsson (2018) <sup>54</sup>	Sweden	113	Questionnaire	Treatment	X	X							
Tan (2019) <sup>55</sup>	UK	104	Questionnaire	Treatment	X	X							
Schulz (2019) <sup>56</sup>	Germany	103	Questionnaire	Treatment	C	X							
Siracusano (2018) <sup>57</sup>	Italy	103	Questionnaire	Treatment	X	X							
Kretschmer (2017) <sup>58</sup>	Germany	100	Questionnaire	Treatment	X	X							
Kitamura (2020) <sup>59</sup>	Japan	99	Questionnaire	Treatment	X	X							
Rammant (2022) <sup>60</sup>	USA	99	Questionnaire	Treatment	X				X	X	X		
Dellabella (2018) <sup>61</sup>	Italy	95	Questionnaire	Treatment	X								
Mostafid (2020) <sup>62</sup>	UK	82	Questionnaire	Treatment	X	X							
Taarnhøj (2021) <sup>63</sup>	Denmark	79	Questionnaire	Treatment	X	X					X		



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Fuschi (2021) <sup>64</sup>	Italy	78	Questionnaire	Treatment	X	X							
Cerruto (2018) <sup>65</sup>	Italy	77	Questionnaire	Treatment	X	X							
Abozaid (2022) <sup>66</sup>	UK	76	Questionnaire	Treatment	X	X							
Tostivint (2021) <sup>67</sup>	France	73	Questionnaire	Treatment	X	X							
Siracusano (2019) <sup>68</sup>	Italy	73	Questionnaire	Treatment	X	X							
Volz (2021) <sup>5</sup>	Germany	72	Questionnaire	Treatment	X	X							
Cheng (2021) <sup>69</sup>	USA	58	Questionnaire	Treatment	X	X							
González-Padilla (2021) <sup>70</sup>	Spain	56	Questionnaire	Treatment	X	X							
Kaye (2020) <sup>71</sup>	USA	54	Questionnaire	Treatment	X	X							
Mastroianni (2021) <sup>72</sup>	Italy	51	Questionnaire	Treatment	X	X							
Catto (2021) <sup>73</sup>	UK	50	Questionnaire	Treatment	X								
Huddart (2017) <sup>74</sup>	UK	45	Questionnaire	Treatment	X	X							
Liedberg (2022) <sup>75</sup>	Sweden	44	Questionnaire	Treatment		X							
Biardeau (2020) <sup>76</sup>	France	40	Questionnaire	Treatment	X	X							
Rose (2021) <sup>77</sup>	USA	39	Questionnaire	Treatment	X	X							
Ziegelmueller (2020) <sup>78</sup>	Germany	35	Questionnaire	Treatment	X	X							
Bosschieter (2019) <sup>79</sup>	Netherlands	28	Questionnaire	Treatment	X	X							
Frees (2018) <sup>80</sup>	Canada	27	Questionnaire	Treatment	X			X					
Ebbing (2018) <sup>81</sup>	Germany	27	Questionnaire	Treatment	X	X							

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Pattou (2022) <sup>82</sup>	France	23	Questionnaire	Treatment	X	X							
Feuerstein (2019) <sup>83</sup>	USA	16	Questionnaire	Treatment	X	X					X		
Hockman (2020) <sup>84</sup>	USA	13	Questionnaire	Treatment				X	X	X			
Tuderti (2020) <sup>85</sup>	Italy	11	Questionnaire	Treatment	X	X							
Miyake (2022) <sup>86</sup>	Japan	10	Questionnaire	Treatment	X	X							
Catto (2021) <sup>87</sup>	UK	1796	Questionnaire	Health related quality of life	X	X							
Yu (2019) <sup>88</sup>	UK	1160	Questionnaire	Health related quality of life	X	X		X		X			
Tsai (2021) <sup>89</sup>	Taiwan	343	Questionnaire	Health related quality of life	X								
Draeger (2018) <sup>103</sup>	Germany	301	Questionnaire	Health related quality of life						X	X		
Suppanuntaroek (2020) <sup>104</sup>	Japan	205	Questionnaire	Health related quality of life	X	X							
Taarnhøj (2020) <sup>105</sup>	Denmark	78	Questionnaire	Health related quality of life	X	X							
Chung (2019) <sup>99</sup>	Canada	586	Questionnaire	Healthcare service	X	X			X	X	X		
Gopalakrishna (2017) <sup>90</sup>	USA	472	Questionnaire	Lifestyle	X	X		X					
Gopalakrishna (2018) <sup>91</sup>	USA	459	Questionnaire	Lifestyle	X	X		X					
Chung (2020) <sup>92</sup>	Canada	235	Questionnaire	Lifestyle	X	X		X					
Lauridsen (2022) <sup>106</sup>	Denmark	104	Questionnaire	Lifestyle	X								
Kukreja (2022) <sup>93</sup>	USA	488	Questionnaire	Diagnosis		X							
Smith (2019) <sup>94</sup>	USA	304	Questionnaire	Diagnosis		X					X		

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Ehlers (2021) <sup>95</sup>	USA	226	Questionnaire	Costs to patients				X				
Casilla-Lennon (2018) <sup>96</sup>	USA	138	Questionnaire	Costs to patients	X	X		X				
Hussain (2021) <sup>97</sup>	UK	117	Questionnaire	Complementary therapy	X	X						
Silverdale (2019) <sup>98</sup>	UK	38	Questionnaire	Complementary therapy	X	X						
Li (2019) <sup>100</sup>	USA	211	Questionnaire	Decision making			X					
Mohamed (2020) <sup>101</sup>	USA	25	Questionnaire	Education				X	X			

## Abbreviations and terminology

ASGS	The Australian Statistical Geography Standard from the Australian Bureau of Statistics, defines remoteness and urban/rural definitions in Australia
CCDR	Centre for Community-Driven Research
dF	Degrees of Freedom. The number of values in the final calculation of a statistic that are free to vary.
f	The F ratio is the ratio of two mean square values, used in an ANOVA comparison. A large F ratio means that the variation among group means is more than you'd expect to see by chance.
HER2	Human epidermal growth factor receptor 2
FOP	Fear of Progression. Tool to measure anxiety related to progression
IQR	Interquartile range. A measure of statistical dispersion, being equal to the difference between 75th and 25th percentiles, or between upper and lower quartiles.
p	Probability value. A small <i>p</i> -value (typically $\leq 0.05$ ) indicates strong. A large <i>p</i> -value ( $> 0.05$ ) indicates weak evidence.
PEEK	Patient Experience, Expectations and Knowledge
PIH	Partners in Health
SD	Standard deviation. A quantity expressing by how much the members of a group differ from the mean value for the group/
SEIFA	Socio-Economic Indexes for Areas (SEIFA) ranks areas in Australia according to relative socio-economic advantage and disadvantage. This is developed by the Australian Bureau of Statistics.
SF36	Short Form Health Survey 36
t	t-Statistic. Size of the difference relative to the variation in your sample data.
Tukey HSD	Tukey's honestly significant difference test. It is used in this study to find 10 significantly different means following an ANOVA test.
W	The W statistic is the test value from the Wilcoxon Rank sum test. The theoretical range of W is between 0 and (number in group one) x (number in group 2). When W=0, the two groups are exactly the same.
$\chi^2$	Chi-squared. Kruskal-Wallis test statistic approximates a chi-square distribution. The Chi-square test is intended to test how likely it is that an observed distribution is due to chance.

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