

Supplementary data one – Questionnaire to the general public

Exploring the public's information needs on medicines development

This survey has been developed by a team of collaborators (from public and private organisations) who are led by the University of Manchester and the European Genetic Alliances Network as part of their work on a European Commission and Innovative Medicines Initiative funded project - the European Patients' Academy on Therapeutic Innovation (EUPATI) (www.patientsacademy.eu).

EUPATI aims to develop more reliable and accessible information for patients and the public on the development of medicines by the pharmaceutical industry. The project came about due to recognition that medicines development is a long, complex and expensive process. This can make it difficult for patients and the public to be aware of, to understand or to get involved in it.

Developing better information for patients and the public will play an important role in increasing their awareness of, and involvement in medicines development, which will lead to better, safer treatments and to more patient focused research and outcomes. Therefore, to develop useful, reliable and accessible information for the public, we are undertaking this survey to find out your current interest, knowledge, awareness and experience of medicines development, to identify your information needs and your preferences for information format.

The results will be written into a report and will feed into the development of materials for patients and the public around medicines development.

Your answers are confidential. Individual responses will never be presented or disclosed. The University of Manchester will only receive anonymised data from ICM. We will share the combined results with patient groups and present summarised findings at conferences and in journal publications, press and newsletter articles. Data will be securely and confidentially stored by ICM and by Nowgen, in accordance with the University of Manchester's data protection policies.

By proceeding to the next screen, you confirm that you have read, understood and accept the description of the survey above and are happy to proceed.

Happy to proceed

Not happy to proceed (CLOSE)

Thank you for agreeing to complete this survey. We would like to start with a few questions on your experiences of pharmaceutical medicines development.

1. Have you been, or are you currently involved in medical research?
By medical research we mean 'studies that explore the causes of illnesses and diseases or develop and test new treatments in humans'.

Yes	
No	

2. How would you rate your current knowledge of medicines research and development?

1	2	3	4	5
I have not heard of it				My knowledge is very good

3. Below are some descriptions of aspects of medicines research and development. Please read each description and rate your current level of knowledge of each area

	1	2	3	4	5
	I have not heard of it		I have some knowledge		My knowledge is very good
Drug discovery - <i>Scientists increase their understanding of a disease by finding out which genes or proteins are affected. They then search for a compound that may act on the affected genes or proteins. This compound can become a new medicine</i>					
Medicine safety - <i>The process of detecting, understanding and preventing side effects</i>					
Patients' roles and responsibilities in medicines development <i>Exploring the range of ways in which patients and the pharmaceutical industry can work together to develop new medicines</i>					
Personalised medicine - <i>Using information about a patient's genetic make-up to select the medicine which will be most suitable to them</i>					
Predictive medicine - <i>Using information about a person's genetic make-up to predict whether they are likely to be affected by a particular disease</i>					
Design and objectives of clinical trials - <i>Studies which test how well new medical approaches for example, medicines and vaccines, might work in people</i>					
Health technology assessment - <i>Exploring how successful a new</i>					

<i>approach (e.g. medicine), is in preventing, diagnosing or treating disease</i>					
Pharmacoeconomics - <i>Identifying, measuring and comparing the costs, risks and benefits of medicines against alternatives and then deciding which option is best for the resources invested</i>					
National and local regulation of new medicines - <i>The organisations and laws that ensure that new medicines work and are acceptably safe, thereby protecting the public's health</i>					

4. Which aspects of medicines development would you like to learn more about?

	Not interested				Very interested
	1	2	3	4	5
Drug discovery - <i>Scientists increase their understanding of a disease by finding out which genes or proteins are affected. They then search for a compound that may act on the affected genes or proteins. This compound can become a new medicine</i>					
Medicine safety - <i>The process of detecting, understanding and preventing side effects</i>					
Patients' roles and responsibilities in medicines development - <i>Exploring the range of ways in which patients and the pharmaceutical industry can work together to develop new medicines</i>					
Personalised medicine - <i>Using information about a patient's genetic make-up to select the medicine or form of treatment which will be most suitable to them</i>					
Predictive medicine - <i>Using information about a person's genetic make-up to predict whether they are likely to be affected by a particular disease</i>					
Design and objectives of clinical trials - <i>Studies which test how well new medical approaches for example, medicines and vaccines, might work in people</i>					

Health technology assessment - <i>Exploring how successful a new approach (e.g. medicine), is in preventing, diagnosing or treating disease</i>					
Pharmacoeconomics - <i>Identifying, measuring and comparing the costs, risks and benefits of medicines against alternatives and then deciding which option is best for the resources invested</i>					
National and local regulation of new medicines - <i>The organisations and laws that ensure that new medicines work and are acceptably safe, thereby protecting the public's health</i>					

5. Which of the following information sources do you currently use to find out information about medical issues?
(Please tick all that apply)

Information websites	
Wiki library e.g. Wikipedia	
Social media e.g. Facebook, Twitter etc.	
YouTube	
Online patient communities	
E-learning	
Educational tools	
Presentations	
Leaflets	
Books or booklets	
Magazine articles	
Newspaper articles	
Television shows	
Radio shows	
Videos or film	
Cartoons	
Public lectures and conferences	
Training courses	
Doctor or other health professional	
Other (please specify)	

6. Which of the following formats would you be interested in using to learn more about medicines research and development?

	Not interested				Very interested
	1	2	3	4	5
Information websites					
Wiki library e.g. Wikipedia					
Social media e.g. Facebook, Twitter etc.					
YouTube					
Online patient communities					
E-learning					
Educational tools					
Presentations					
Leaflets					

Books or booklets					
Magazine articles					
Newspaper articles					
Television shows					
Radio shows					
Videos or film					
Cartoons					
Public lectures and conferences					
Training courses					
Doctor or other health professional					
Other (please specify)					

7. Who would you like to receive information about medicines development from? (Please tick all that apply)

A doctor, nurse or other medical practitioner	
A medical research charity	
A government department	
A public –private partnership	
A family member, friend or colleague	
A journalist or news organisation	
A university or academic institution	
A pharmaceutical company	
A patient advocacy organisation	
A not for profit organisation	
Other (please specify)	

8. How old are you?

18-24	
25-34	
35-44	
45-54	
55-64	

9. What is your gender?

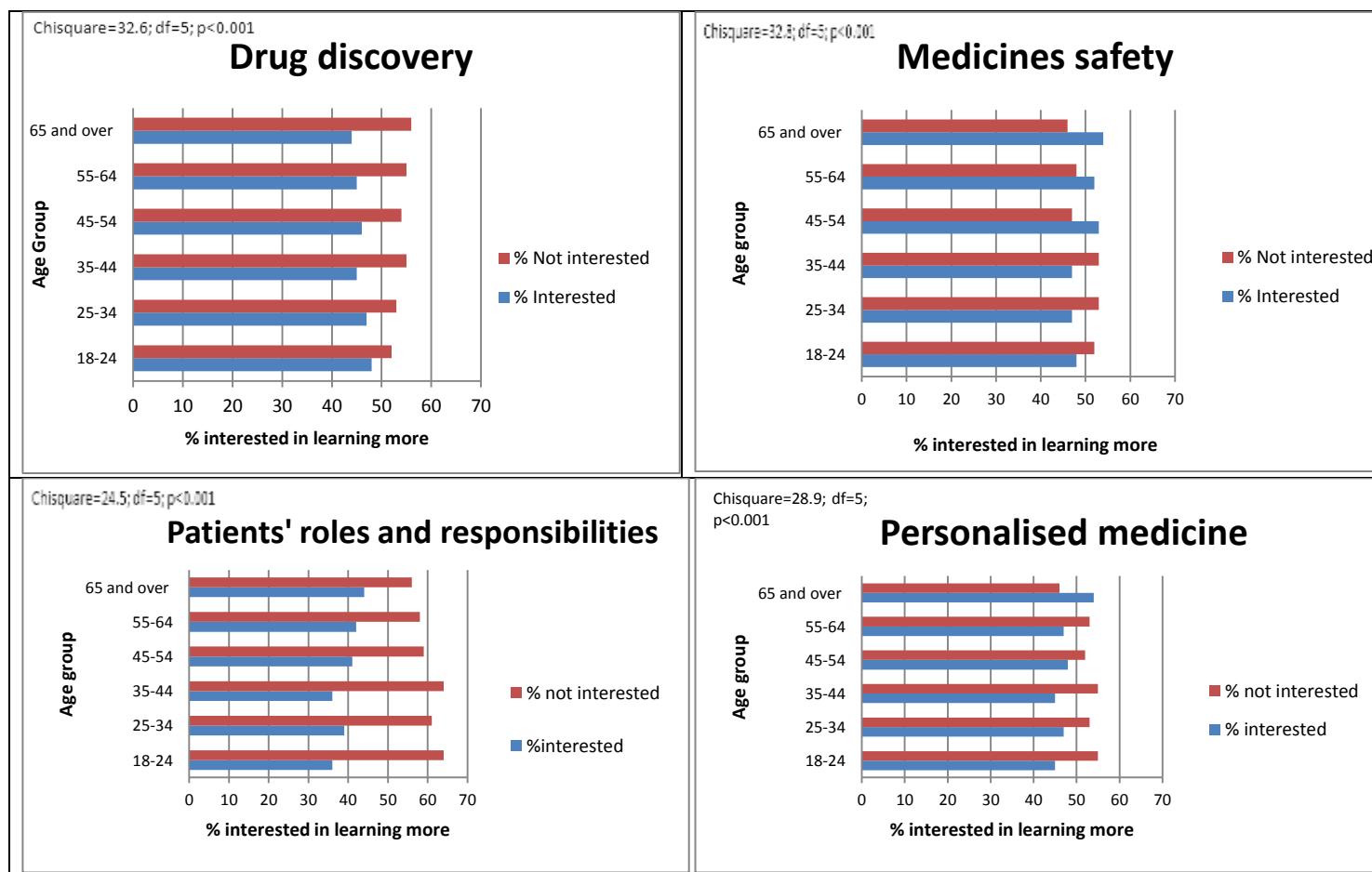
Male	
Female	

Thank you for your contribution

Supplementary data 2 - Relationship between demographic characteristics and previous experience of research

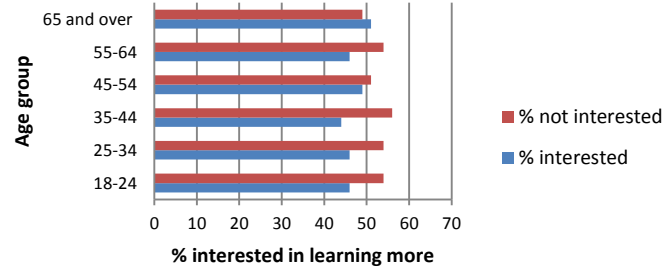
	No previous involvement in medical research N=6358	Currently or previously involved in medical research N=573	Mantel Haenszel Chi square P value	Odds Ratio (95% CI)
Gender				
Female	52% (3307)	42% (239)	22.3; df=1; P<0.001	1.0
Male	48% (3051)	58% (334)		1.51 (1.27, 1.80)
Age group				
18-24 years	13% (814)	20% (116)	5.19; df=1; p<0.05 35.4; df=1; p<0.001 30.6; df=1; p<0.001 12.9; df=1; p<0.001 0.35; df=1; p=ns	1.0
25-34 years	21% (1312)	24% (138)		0.74 (0.57, 0.97)
35-44 years	23% (1473)	16% (89)		0.42 (0.32, 0.57)
45-54 years	21% (1341)	15% (85)		0.44 (0.37, 0.62)
55-64 years	17% (1071)	16% (90)		0.59 (0.44, 0.79)
65 years and over	5% (348)	10% (55)		1.10 (0.77, 1.59)

Supplementary data three – Relationship between age and interest in learning more about aspects of medicines R&D N=6931



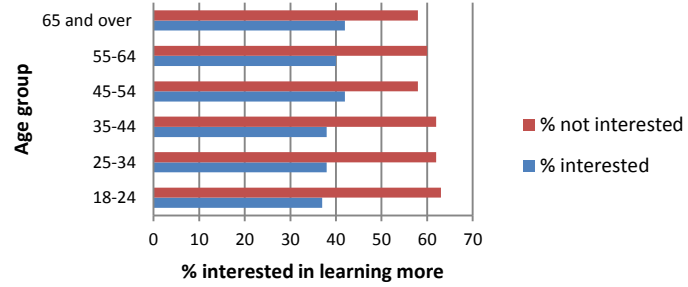
Chisquare=25.9;df=5;p<0.001

Predictive medicine



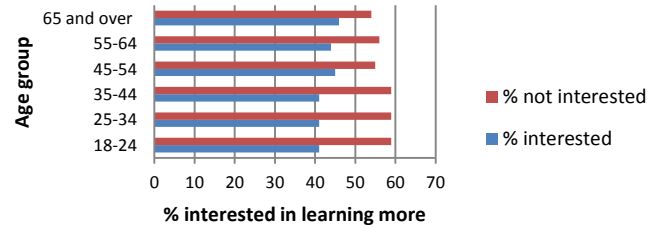
Chi square=12.7; df=5; p<0.05

Clinical trials



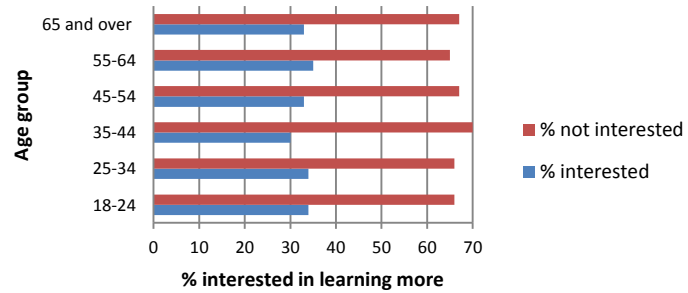
Chisquare=15.3;df=5;p<0.01

Health Technology Assessment



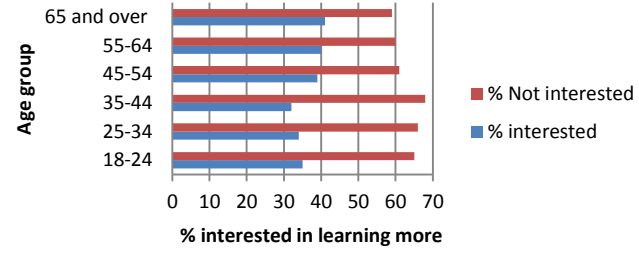
Chi square = 16.3; df=5; p<0.01

Pharmacoeconomics



Chisquare= 40.8;
df=5; p<0.001

Regulation



Supplementary data four – Multivariate analysis tables N=6931

Predictors of reporting good/ very good overall knowledge of medicines R&D (Age group 18-24)

R² =0.04

	Exp (B)	95% CI
Male gender	1.10	(0.96-1.25)
Age – 18-24	1.14	(0.95-1.37)
Experience of medical research	4.87	(4.09-5.84)

Predictors of reporting good/ very good overall knowledge of medicines R&D (Age group 25-34)

R² =0.04

	Exp (B)	95% CI
Male gender	1.10	(0.96-1.25)
Age – 25-34	1.23	(1.06-1.44)
Experience of medical research	4.89	(4.09-5.86)

Predictors of reporting good/ very good overall knowledge of medicines R&D (Age group 35-44)

R² =0.04

	Exp (B)	95% CI
Male gender	1.10	(0.96-1.25)
Age – 35-44	0.98	(0.84-1.15)
Experience of medical research	4.91	(4.10-5.89)

Predictors of reporting good/ very good overall knowledge of medicines R&D (Age group 45-54)

R² =0.04

	Exp (B)	95% CI
Male gender	1.10	(0.96-1.25)
Age – 45-54	0.93	(0.79-1.10)
Experience of medical research	4.90	(4.09-5.87)

Predictors of reporting good/ very good overall knowledge of medicines R&D (Age group 54-65)

R² =0.04

	Exp (B)	95% CI
Male gender	1.10	(0.96-1.25)
Age – 54-64	0.94	(0.78-1.120)
Experience of medical research	4.92	(4.11-- 5.89)

Predictors of reporting good/ very good overall knowledge of medicines R&D (Age group 65 and over)

R² =0.04

	Exp (B)	95% CI
Male gender	1.09	(0.96-1.24)
Age – 65 and over	0.54	(0.39-0.78)
Experience of medical research	5.07	(4.23—6.07)

Supplementary data five - Multivariate analysis tables N=6931

Predictors of reporting interest in learning more about medicines safety (Age group 18-24)

R² =0.06

	Exp (B)	95% CI
Good/very good knowledge of medicines R&D	3.78	(3.26-4.39)
Male gender	0.72	(0.65-0.79)
Experience of medical research	1.20	(0.99-1.45)
Age – 18-24	0.89	(0.77-1.03)

Predictors of reporting interest in learning more about medicines safety (Age group 25-34)

R² =0.06

	Exp (B)	95% CI
Good/very good knowledge of medicines R&D	3.81	(3.28-4.42)
Male gender	0.72	(0.65-0.79)
Experience of medical research	1.19	(0.99-1.44)
Age – 25-34	0.84	(0.75-0.95)

Predictors of reporting interest in learning more about medicines safety (Age group 35-44)

R² =0.06

	Exp (B)	95% CI
Good/very good knowledge of medicines R&D	3.78	(3.26-4.38)
Male gender	0.72	(0.65-0.79)
Experience of medical research	1.18	(0.98-1.42)
Age – 35-44	0.86	(0.77-0.97)

Predictors of reporting interest in learning more about medicines safety (Age group 45-54)

R² =0.06

	Exp (B)	95% CI
Good/very good knowledge of medicines R&D	3.79	(3.27-4.40)
Male gender	0.72	(0.65-0.79)
Experience of medical research	1.20	(1.00-1.45)
Age – 45-54	1.22	(1.08-1.38)

Predictors of reporting interest in learning more about medicines safety (Age group 55-64)

R² =0.06

	Exp (B)	95% CI
Good/very good knowledge of medicines R&D	3.78	(3.26-4.39)
Male gender	0.72	(0.65-0.79)
Experience of medical research	1.19	(0.99-1.44)
Age – 55-64	1.16	(1.02-1.33)

Predictors of reporting interest in learning more about medicines safety (Age group 65 and over)

R² =0.06

	Exp (B)	95% CI
Good/very good knowledge of medicines R&D	3.81	(3.28-4.42)
Male gender	0.72	(0.65-0.80)
Experience of medical research	1.17	(0.97-1.42)
Age – 65 and over	1.28	(1.04-.1.50)