

# Patient Public Involvement Engagement – A Comprehensive Approach to Health Economics and Outcome Research Evidence Collection and Analysis

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## BACKGROUND

- In the 2002 paper ‘Revealing the cost of Type II diabetes in Europe’, <sup>1</sup> Bengt Jönsson, on behalf of the Cost of Diabetes in Europe – Type II (CODE-2) advisory board, published the first co-ordinated attempt to measure the cost of people with Type II diabetes.
- In 2015, the importance of patient and public involvement and engagement (PPIE) was published. <sup>2</sup>
- HCD Economics (HCD) affiliated with the University of Chester UK (UoC), has subsequently undertaken a number of global burden studies utilising the CODE 2 and PPIE framework within an expert review group (ERG) in study design, interpretation and utility.

## METHODS

- The ‘bottom-up’ prevalence-based societal burden studies have two objectives, primary; quantifying annual direct medical and non-medical costs plus indirect costs, secondary; impact on health-related quality of life.
- Data are collected by means of two questionnaires: physician on-line clinical record form (CRF), and the paper and pen patient and public involvement and engagement form.
- The CRFs collect information on; direct medical resource utilisation for a 12 month period, clinical data based on recorded notes and demographics.
- For each CRF completed, the corresponding patient completes the PPIE form covering; out-of-pocket expenses and work loss (direct non-medical and indirect costs), as well as information on quality of life, therapy adherence and psychosocial burden.
- Each study is governed by an expert review group consisting of charity representatives, university representatives, medics and health economists.
- Each study is submitted to the UoC Faculty of Health and Social Care Research Ethics Committee for approval and conducted in accordance with relevant European guidelines.

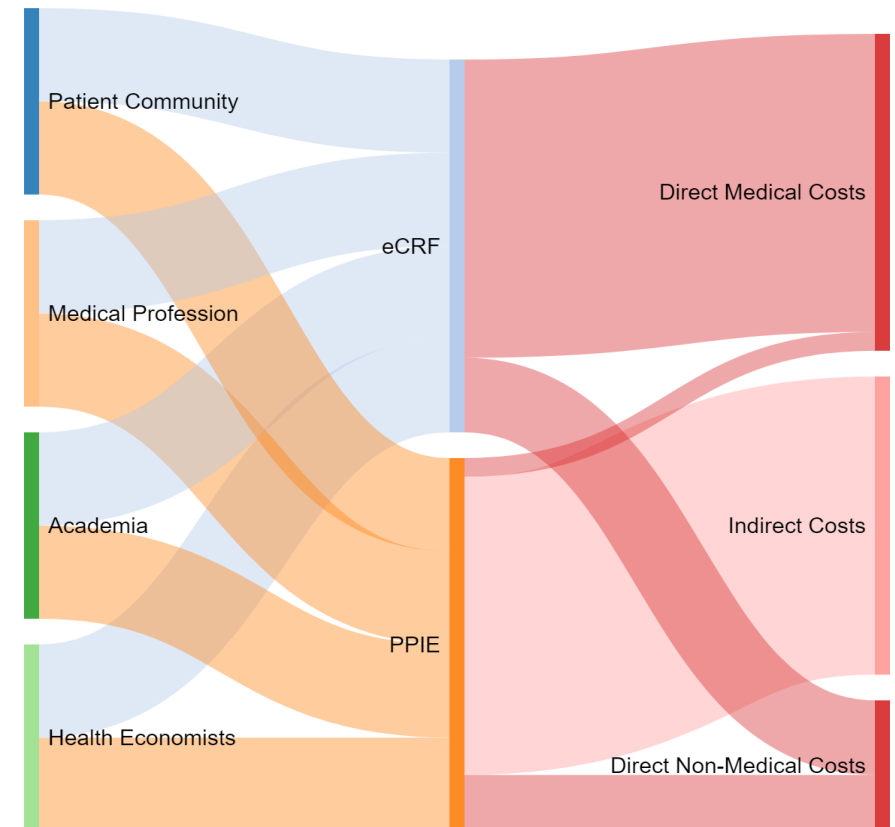
## RESULTS

- Each study enables the production of a granular database comprehensively detailing the wide variety of costs that accompany a disease.
- Per-patient costs are calculated by multiplying the quantities of the resource use collected in the study with the national unit price of each resource.
- Costs associated with temporary and long-term work absence (including early retirement) are valued using the traditional human capital approach.

## CONCLUSIONS

- These studies provide a comprehensive evidence base which supports and supplements community efforts in; lobbying for maintenance of and improvement of treatment, service provision reviews, political messaging and public health actions.
- This evidence base facilitates patient involvement and also supports and supplements communications with payers.
- The findings are disseminated in peer review publications to inform the international community.

Figure 1. Schematic of methods



## REFERENCES

1. Jönsson, B. Articles Revealing the cost of Type II diabetes in Europe. *Diabetologia* (2002) 45:S5-S12. DOI 10.1007/s00125-002-0858-x
2. Ocloo, J. From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. [qualitysafety.bmj.com](http://qualitysafety.bmj.com)

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