Index

Aboriginal health system 6–7
- colonization and health status 81–3
- community controlled 86–90
decolonizing/re-empowerment policy 90–93
- policies, impositions and consultation 83–6
see also Australian health system
Abortion Counselling Service ('Jane') 20–21
ABPI (Association of British Pharmaceutical Industry) 246
ACCHO (Aboriginal Community Controlled Health Organisations) 7, 84, 86–92
activist groups
- forming alliances 115–16, 151–3, 155–6
- sociological perspective 15–21
governance and 21–4
- potential actionable forms 26–7
- problems of aggregative democracy 24–6, 152
- in Victoria, Australia 182–3
see also consumer groups; civil society
Adams, Karen 6–7, 81
Africa 64, 67–8
Alford, R. 31, 166, 178
- alliances 115–16, 151–3, 155–6
- Alzheimer Society of Ireland 99
Armstrong, Wendy 10–11, 193
Australian health system 10, 177–89
- consumer groups, rise of 182–5
- and influence over medicines policy 185–8
development of 179–82
see also Aboriginal health system
Austrian health system 9, 143–58
- consumer groups 147–51
- condition-specific 153–5
cross-condition alliances 155–6
- political activism and 151–3
- form of, and role of consumers 144–7
- overview 156–8
- and prevailing political norms 143–4
- stakeholder perspectives 156
BAG (Bundesarbeitsgemeinschaft) Selbsthilfe 134, 137
Baggott, Rob 5, 30, 211
Bal, Roland 7–8, 111
Barraclough, Simon 9–12, 161
Batt, S. 203–4, 243, 250
Bentsen, Lloyd 55
biomedical R&D 247–9
Braithwaite, John 187
Braundegger-Kallinger, Gudrun 9, 143
Breakthrough Breast Cancer 43
Brendtro, M.J. 234
Bristol-Myers Squibb 74–5
British Council of Disabled People 20
British Medical Journal 242
Brown, M. 19
Brown, P. 161, 210
CADTH (Canadian Agency for Drugs and Technologies in Health) 246
Canadian health system 10–11, 19, 193–205
- consumer group strategies 201–2
- funding and partnerships 202–4, 242, 246, 250
- from local to regional governance 200–201
- history of 193, 196–200
- overview 204–5
shifting state/citizen relationship 194–6

cancer 21, 40, 43, 48

CAP (Consumers’ Association of Penang) 161, 163, 169–70, 172–4

Carboni, N. 51

CHF (Consumers’ Health Forum of Australia) 183, 184–5, 245

CHI (Citizen’s Health Initiative) 171

Church, John 10–11, 193

CIL (Centers for Independent Living) 231–2

Cipla 67

civil society

forms of citizenship rights 18
governance and 64–5

participation, EU example 49–50, 52–5

prior to state funded health care,

Canadian example 196–200

see also activist groups; consumer groups

COAG (Council of Australian Governments) 92

Coalition Against Health Care Privatization 171

‘conflict capacity’ 152

consumer groups

and public health organizations,

EU example 50–51

issues of concern 55–8

coop-option, ethics of 239–42

Australian example 177–8, 184, 186–7

biomedical R&D 247–9

regulatory policies 244–5

collective organization 113–14

rationale, role and function,

Malaysian example 165–6

term and definitions 2–3, 4, 103, 177, 209

see also activist groups; civil society; individual countries’ names

Consumer Powerhouse 56–7

consumer protection societies 134–5

cooperatives 196–7

Crouch, H. 162

Cystic Fibrosis Foundation 249

Danzon, Marc 145

Daw, Christina Nuñez 11–12

DDB (Deutscher Diabetiker Bund) 132–3, 135–6

de Leeuw, Evelyne 10, 177

de Sousa Santos, B. 98

Delnoij, Diana 7–8, 111

democracy 64–6

liberal and collectivist streams of

1–2, 12–13

problems of representation 24–6, 152, 226

DG Enterprise 51

DG Sanco 48, 50–51, 56

DGVP (Deutsche Gesellschaft für Versickerte und Patienten) 135

diabetes 132–3

disabilities and marginalized groups 19–20, 25, 40, 134, 231–4

disease-specific patient organizations 132–3, 153–5, 248–9

disempowerment of scale 66–8

doctor organizations 34–5, 121–2, 129–30, 131, 145–6, 154, 197–9

DPWV (Deutscher Paritätischer Wohlfahrtsverband) 134, 137

Drumm, Brendan 97–8, 101

Dryzek, J.S. 178–9

Dutch health system 111–23

activities and alliances of patient organizations 115–16

empowering patients and giving choice 111–13

challenges of changing system 116–18

expectations and outcomes 121–3

organization 113–14

public reporting of service performance 119–20

patients’ use of 120–21

EAG (Expert Advisory Groups), Ireland 97–8, 102–5

ECJ (European Court of Justice ) 48

Ecuador 69

Edwards, Rebecca 6–7, 81

EFPIA (European Federation of Pharmaceutical Industries and Associations) 245–6
Index

EMA (European Medicines Agency) 246–7, 248
Enlightenment influences 64–6
environmental issues 75
EPHA (European Public Health Alliance) 50
Epstein, S. 247
ESRC (Economic and Social Research Council) 30
ESRC project 31–44
consumer groups’ impact on policy 35–9, 43–4
interaction between groups 33 and government departments 33–4
and other stakeholders 34–5
key characteristics of groups 32–3
and organizational changes 39–41
EU (European Union) health systems
civil society participation, politics of 52–5
consumers and public health organizations 50–51
issues of concern 55–8
globalization and policy processes 51–2
governance issues 47–8
citizen participation 49–50
EU 2020 Agenda 54
stakeholder participation 52–5, 245, 246–7
White Paper on European Governance (EC) 49, 52–3
EU Health Forum 50–51
European Commission 49, 50, 52–4
European Consumers’ Organisation 48, 54
European Council 49–50
European Parliament 49, 50
European Patients’ Forum 56
EURORDIS (European Organisation for Rare Disorders) 249
experiential knowledge 3–4, 15, 98–9, 112
Faber, M. 120, 121
FDA (Food and Drug Administration) 224–6, 233, 234
Finnish patient organizations 240, 250
FOMCA (Federation of Malaysian Consumer Associations) 161, 167–9, 172–4
Forster, Rudolf 9, 143, 149
Fox, Michael H. 11, 208
Fox, N. 22
FQHCs (Federally Qualified Community Health Centers) 227–9
Fraser, N. 25
Fredericks, Bronwyn 6–7, 81
Freire, Paulo 87
Fudge, Nina 106
funding 41, 56, 92, 115–16, 135–7, 144–5, 154, 168, 184, 203
of patient organizations by pharmaceutical companies 136, 137, 204, 233, 240–42
regulatory policies 244–7
Geissler, Jens 8–9, 127, 152, 250
Gemeinsamer Bundesausschuss 131
German health system 8–9, 127–40
consumer protection societies 134–5
doctors’ organizations and services 129–30
governance 22–4, 130–31
insurance providers 127–9
patient organizations
action of 127
disease-specific (diabetes) 132–3
political influence of 138–40
questions of funding 135–7
senior citizens 134
umbrella organizations 133–4
Global Fund 68
governance
Canada, accountability and 200–201
corporatist polity, in light of insurance provision 22–3, 127–31
in the EU 47–8
global, and key players 63
from government towards governance 21–2
Ireland’s HSE 97–108
state inclusiveness and exclusiveness 178–9
governmentality 23, 121
Greß, S. 22–3

health inequities, causes and action
75–8, 231
HealthInside, poll findings 203
heart-related illness 40
Hirschman, A.O. 152
HIV/AIDS activism 19, 74–5
HSAs (health system agencies) 226–7
HSE (Health Services Executive) 97–8, 99–108

IAPO (International Alliance of Patients’ Organizations) 245
INCADDS (Irish National Council of AD/HD Support Groups) 99
India 69, 70–71, 72–3
insurance provision 55, 111, 121, 122
American experience 55, 208–9, 213–14
Austrian self-governance 144–5, 155
German self-governance 127, 128–9
consumer interests and 139
coverage and benefits 129, 131
funding of patient organizations 136–7
intermediary function of providers 130–31
organizations set up to represent patients 135
International People’s Health University 72
internet 117–18, 224–5
Irish health system 3–4, 7, 97–108
contradictory governmental rationalities 105–6
EAGs, setting up of 97–8
epistemological justice 98–9, 107
managerialist/partnership notions 100–105, 241, 242
National Strategy for Service User Involvement 105–6
Irish Medical News 98, 103
Irvine, R. 181

John, Prem Chandran 6, 61
Jones, Kathryn 5, 30, 151
JSA (Jan Swasthya Abhiyan) 69, 70–71, 72–3
Kansas Health Consumer Coalition 214, 216–18
Kent, Alastair 242
Kingdon, J.W. 233–4
Klawiter, M. 21
KMS (Koori Maternity Services) 90
Koivusalo, Meri 6, 47
Krajic, Kar 9, 143
Lamberton, Anna 11, 208
Landzelius, Kyra 210
Laszews, Robert 218
Latin America 64
Leahy, Michael 10, 177
Legge, David G. 6, 61
LINks (Local Involvement Networks) 37
Lisbon Treaty (2007) 49, 52
Löfgren, Hans 10, 12, 177, 239

Madelkern Group on Better Regulation 53
Malaysian health system 9–10, 161–75
consumer groups
achievements and challenges 172–4
action against privatization 170–72
principal activist group (CAP) 161, 163, 169–70, 172–4
principal national group (FOMCA, 161, 167–9, 172–4
rationale, role and function 165–7
types 161
political system 162–3
from welfarism to pluralism 163–6
funding 168
market fundamentalism 66, 77–8
index

marketization of health care 7–8, 208–9
and choice 113, 119–20, 146, 178
and privatization 164–6, 168, 170–72
public reporting processes and 119–20
see also pharmaceutical companies
Marshall, T.H. 18
Massachusetts Quality Coverage and Quality Care Initiative 230
maternity 90
Medibank 181, 183, 189
Medicare and Medicaid 209, 223, 229
medicines policy, 185–8
mental health, 40, 232–3
Milwea, Timothy, 4–5, 15, 30, 121
Mintzes, Barbara, 242
MSF (Médecines sans Frontières), 74–5
NAHS (National Aboriginal Health Strategy) 84–5
NAM (Non-Aligned Movement) 65
National Health Service see United Kingdom of Great Britain
National Strategy for Service User Involvement 105–6
National Voices 39, 43–4
Naylor, C.D. 198
neo-liberalism 66–7, 77–8, 100, 170–72, 178, 189, 193, 195–6
Netherlands see Dutch health system
New Scientist 241
Newman, J. 23
NGOs (non-governmental organisations) 50, 54, 55–7, 171
NICE (National Institute of Health and Clinical Excellence) 33, 38–9, 41, 55, 248
Novo Nordisk 240
NPM (New Public Management) 3, 181
O’Donovan, Orla 7, 97
Offe, C. 151–2
Olson, Mancur 138
‘organizational capacity’151–2
Ostry, A. 197
Parsons, T. (1951) 17
patient-clinician encounter 17–18
PatientView 242
PCTs (Primary Care Trusts) 37
People’s Charter for Health, The, 69
PHA (People’s Health Assembly) 68, 69
pharmaceutical companies 35, 51
biomedical R&D 247–9
funding of patient organizations 136, 137, 204, 233, 240–42
influence of, legitimation processes 53, 55–7, 67, 74–5, 186–7, 243–4,
250–51
regulatory policies 244–7
see also marketization of health care
PHM (The People’s Health Movement) 61–78
aims and purpose 62, 71–3
as globalization from below 78
health inequities, change and action 75–8
within global governance setting 63
components and organization 69–71
disempowerment thinking 66–8
origins 68–9
political, ideological and economic context 64–6
World Health Organization and 73–4
PHM Globa, 72
Phua, Kai Lit 9–10, 161
Picker Institute Europe 38
Playing by the Rules but Losing 213
PPI (patient and public involvement) 30, 36–9, 43
privatization 164–6, 168, 170–72
Prottas, J. 213
Pryor, C. 213
Ramasamy, P. 162
Rare Disease UK 41
religion 64, 83
Rethink 40
Right to Health campaign 72–3
Rudd, Kevin 85
SAFE (Stroke Alliance for Europe) 42
Saltman, R. 144–5
Sandel, M.J. 194
Schipaanboord, Atie 7–8, 111
schizophrenia 40
senior citizens 40, 134
Snodgrass, D.R. 165
social movement theory 171–2
social rights 19
Specialised Healthcare Alliance 41
Statement of Intent to Close the Gap on Indigenous Health Inequality 85
Steckler, A. 226
Stichweh, R. 152
Story of VACCHO, The 88, 89
TABD (TransAtlantic Business Dialogue) 52
TACD (Transatlantic Consumer Dialogue) 51–2
Taggart, E. 39
tobacco industry 50, 53
Tollefson, E.A. 199
Tomes, N. 223
transparency 52–7, 113, 137, 250–51
TRIPS agreement 67–8
Tritter, Jonathan 6, 47
Truong, Denise 11–12
UAEM (Universities Alliance for Essential Medicines) 74–5
UK health system
activist/consumer groups 15–16, 18, 33
and government departments 33–4, 36–9
and other stakeholders 34–6, 244–5, 246, 248
categories of 211
devolution and European connections 41–2
disability groups 20
funding 41, 241
organizational changes in 39–41
Association of Medical Research Charities 244–5
Care Quality Commission 37–8
democratic deficit’, in 30–31
foundation trusts 37
Local Government and Public Involvement in Health Act (2007) 38
UK Stroke Association 42
umbrella organizations 133–4, 137
United States of America, health system 11–12, 51
activist groups 20–21, 74–5
disabled community and mental health 231–4
consumers/consumerism action and potential of 218–19
analyses of 210–11, 22–3
importance of input, examples 229–31
Kansas consumer group, case study 214–18
meaning, motivation and function 211–14, 234–5
historical background 208–10
insurance provision 55, 208–9, 213–14
pharmaceutical companies 55–6, 241
public sponsored health programmes 223–4
FDA (Food and Drug Administration) 224–6
FQHCs (Federally Qualified Community Health Centers) 227–8
HSAs (health system agencies) 226–7
Medicaid 209, 223, 229
Protection and Advocacy agencies 228–9
VACCHO (Victorian Aboriginal Community Controlled Health Organisations) 7, 84, 86–92
VACKH (Victorian Aboriginal Council on Koori Health) 90–92
Vaillancourt Rosenau, Pauline 11–12
VHA (Veterans Health Administration) 224
Vitry, Agnes 12, 239

Hans Löfgren, Evelyne de Leeuw and Michael Leahy - 9780857931818
Downloaded from Elgar Online at 02/15/2019 03:32:16AM via free access
<table>
<thead>
<tr>
<th>Index</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>VKVD (Verband der Krankenversickerten Deutschlands)</td>
<td>135</td>
</tr>
<tr>
<td>Voices for Health Care</td>
<td>216</td>
</tr>
<tr>
<td>Wallerstein, N.</td>
<td>87</td>
</tr>
<tr>
<td>Ward, K.</td>
<td>22</td>
</tr>
<tr>
<td>Weber, M.</td>
<td>64</td>
</tr>
<tr>
<td>White Paper on European Governance (EC)</td>
<td>49, 52–3</td>
</tr>
<tr>
<td>WHO (World Health Organization)</td>
<td>73–4</td>
</tr>
<tr>
<td>World Bank</td>
<td>74</td>
</tr>
<tr>
<td>WTO (World Trade Organization)</td>
<td>67–8</td>
</tr>
<tr>
<td>Yale University</td>
<td>74–5</td>
</tr>
<tr>
<td>Young, I.</td>
<td>25</td>
</tr>
<tr>
<td>Zavestoski, S.</td>
<td>161, 210</td>
</tr>
</tbody>
</table>